Strengthening Newborn Health and Prevention of Birth Defects

Report of regional network meeting in South-East Asia

23–25 April 2013, New Delhi, India

World Health Organization
Regional Office for South-East Asia

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South-East Asia Regional Network Meeting on Strengthening Newborn Health and Prevention of Birth Defects

23–25 April 2013, New Delhi, India

World Health Organization
Regional Office for South-East Asia

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Printed in India

Contents

Annexes

Acronyms

AIIMS	All India Institute for Medical Sciences
apps	application
ASHA	Accredited Social Health Activist
CDC	Centers for Disease Control and Prevention, Atlanta, USA
CRS	congenital rubella syndrome
FFI	Food Fortification Initiative
HMIS	Health Management Information System
ICD	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICDDR,B	International Centre for Diarrhoeal Disease Research, Bangladesh
MDG	Millennium Development Goal
MMR	measles, mumps and rubella (vaccine)
MR	measles and rubella (vaccine)
NNPD	neonatal-perinatal database
NTD	neural tube defect
RCH	reproductive and child health
RMNCH+A	reproductive, maternal, neonatal, child health and adolescent health

SAARC	South Asian Association for Regional Corporation
SEAR	South-East Asia Region of WHO
SEARO	WHO South-East Asia Regional Office
SNCU	special newborn care unit
STP	standard treatment protocol
UNICEF	United Nations Children's Fund
WHO	World Health Organization
YLD	years without a disability

Executive summary

Although there has been significant progress in the reduction of child mortality in the World Health Organization Office for South-East Asia Region over the last two decades, neonatal mortality remains high. One million newborns die every year in the Region, that is one third of the global burden. In response, the WHO Regional Office has taken several initiatives to support Member States to strengthen national newborn health programmes. One of the most significant of these has been to establish a regional network of institutions for newborn health. The network has been instrumental in developing training materials and tools for strengthening newborn health care in the Region. Corresponding national networks for newborn health have since been initiated in Bangladesh, Myanmar and Nepal. Furthermore, a regional neonatal-perinatal databse has been developed in order to generate epidemiological information.

The South-East Asia Regional Strategic Framework on the Prevention and Control of Birth Defects was published in 2013. To support implementation of this strategy, it is planned to establish a Regional Network on Birth Defects to function along similar lines to, and in close collaboration with the Regional Network on Newborn Health. In addition, birth defects would be integrated in the existing neonatal-perinatal database to be used by member institutions of the two networks. Capacity-building tools would also be developed by the Regional Birth Defects Network to support the development and implementation of birth defects programmes in the countries.

In this context, a regional network meeting on strengthening newborn health and prevention of birth defects was held on 23–25 April 2013 in New Delhi, India. The meeting aimed to review progress in the establishment of national neonatal-perinatal networks; to disseminate educational and training tools on newborn health; to discuss the Regional Strategic Framework on the Prevention and Control of Birth Defects; to establish regional and national networks on the prevention of birth defects; and to identify linkages with the regional network on newborn health. Participants included national programme managers for newborn health and birth defects from 10 of the 11

Member States of the Region, members of the Regional Network on Newborn Health, WHO staff from the Regional and Country Offices, birth defects experts, the United States Centers for Disease Control and Prevention (CDC), and representatives from United Nations agencies and other partner organizations.

The participants agreed that, while implementation of existing evidence-based interventions to reduce newborn mortality remained important, prevention of birth defects needed to be recognized as a public health priority to achieve Millennium Development Goal 4 and to sustain progress beyond 2015. Based on the progress and role of the Regional Network on Newborn Health, it was recommended to establish a Regional Network on Birth Defects which would be coordinated by the WHO Collaborating Centre for Genetics at the All India Institue for Medical Sciences, New Delhi, India. This Network would work in close collaboration with the existing Regional Network on Newborn Health being coordinated by the WHO Collaborating Centre on newborn health at the same institute.

Recommendations were developed for Member States as well as for WHO, CDC and other partners. In addition, proposed action plans for the next few years were developed by each participating country.

1. Introduction

Every year, 1 million of the 3 million global neonatal deaths occur in the South-East Asia Region (SEAR). An equal number of stillbirths also take place annually in the Region. High coverage of an evidence-based intervention could avert the majority of these deaths.

Among the approaches taken by the World Health Organization (WHO) South-East Asia Regional Office (SEARO) to promote newborn health has the provision of capacity building and catalytic support to centres of excellence in Member States to create a regional resource. Through regional meetings held in 1998, 2002 and 2011, SEARO has brought the newborn health leadership of the Region together to form the Regional Network on Newborn Health. The Network has been instrumental in developing a neonatal-perinatal database, learning resource materials and packages for newborn care, and standard treatment protocols to manage common newborn conditions in small hospitals that have contributed to strengthen newborn health care in the Region.

The regional neonatal-perinatal database generates prospective information on neonatal/perinatal morbidity and mortality using standardized tools for data collection and analysis. New insights into the profile of neonatal and perinatal epidemiology were also generated. Subsequently, the establishment of corresponding national networks for newborn health has been initiated in Bangladesh, Myanmar and Nepal.

SEARO has recently published the Regional Strategy for Prevention and Control of Birth Defects (2013–2017) in collaboration with Member States. To support implementation of the strategy, it is proposed to establish a Regional Network on Birth Defects for surveillance and prevention. This Network will be established based on the experience of the Regional Network on Newborn Health, and with which it will function in close collaboration. A common database is to be developed for use among the member institutions of the two networks. In addition, capacity-building tools are planned to support the development and implementation of birth defects programmes in the countries.

In this context a regional network meeting on strengthening newborn health and prevention of birth defects was organized by the WHO Collaborating Centre, the All India Institute for Medical Sciences (AIIMS), on 23–25 April 2013, in New Delhi, India. This meeting was supported by WHO-SEARO in collaboration with CDC. The main aim was to develop a collaborative approach to strengthen efforts of Member States and WHO in the Region, to address newborn mortality by addressing newborn health and birth defects in a convergent manner, to develop consensus to establish Regional Birth Defects Network and to define the coordination mechanisms between the two Regional Networks.

Participants included country programme managers for newborn health and birth defects (from Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste), neonatal-perinatal experts who are members of the Regional Newborn Health Network, birth defects experts, and representatives from United Nations agencies, partner organizations, AIIMS, CDC and WHO Regional and Country Offices.

1.1 Objectives

The objectives of this regional meeting, presented by Dr Neena Raina, Regional Adviser for Child and Adolescent Health and Development, SEARO, were:

(1) To review progress in the establishment of national neonatal-perinatal networks for strengthening newborn care, and in promoting evidence-based newborn heath care, education and training in the Member States and across the Region.

(2) To share educational and training tools on newborn health, such as e-courses, webinars, standard treatment protocols and recent WHO guidelines.

(3) To disseminate the Regional Strategic Framework for Prevention and Control of Birth Defects, 2013–2017, and to develop an outline of priority steps to initiate preventive strategies for birth defects in the countries.

(4) To develop consensus on the establishment of a regional and national networks on prevention of birth defects and identify linkages with the Regional Network on Newborn Health.

2. Inaugural session

Dr Vinod K Paul welcomed the participants on behalf of the AIIMS WHO Collaborating Centre, which hosted the meeting with support from SEARO and CDC. He said that in 1992, India was among the first developing countries to include newborn health as a national health priority. He noted the importance of identifying core strategies for prevention and management of birth defects and emphasized that this will strengthen the newborn health programmes.

Following an introduction of all participants, Dr Raina reviewed the objectives and the agenda of the meeting. Impressive progress had been made in the SEAR to decrease child and infant mortality. However, neonatal mortality is still high and the decline is stagnant, and overall birth defects contribute about 4-7% to neonatal mortality. As institutional delivery is now getting universal and birth asphyxia prevalence is decreasing, birth defects contribute to 22% of neonatal deaths in some countries. There has been an significant progress in birth defects prevention work in the Region in collaboration with CDC. Several regional and national level meetings had been conducted: a regional expert group meeting in late 2011, regional programme managers meeting in March 2012, regional workshop on birth defects surveillance in April 2012, and the meeting on the Sri Lanka national plan on birth defects prevention in April 2013. Furthermore, countries are also establishing national networks with related activities planned before the end of 2013. The number of policy-makers and national programmes interested in birth defects is also expanding, and multidisciplinary efforts are now getting ready to address the challenges of birth defects.

Dr Joseph Sniezek affirmed CDC's commitment to supporting work to prevent birth defects, with a focus on strengthening surveillance and research. He said that while the cause of many birth defects remained unknown, there was good evidence on how to prevent a significant percentage of them. For example, experience from the United States of America and other countries shows that 150 000–200 000 neural tube defects can be prevented each year with folic acid food fortification. Dr Sniezek extended CDC support for the SEAR birth defects prevention initiative, including development of the Strategic Framework and surveillance training that is being conducted at both regional and country levels.

Dr Sangay Thinley, Director of Family Health and Research, SEARO noted the 50% reduction in under-five mortality in the SEAR, but stressed the need to do more to meet the United Nations Millennium Development Goal 4 (MDG4) of a two thirds reduction. He said that one of the major unresolved problems was the high neonatal mortality in the Region, which WHO was addressing through the Strategic Framework for Prevention and Control of Birth Defects. Specifically SEARO was focusing on home- and facility-based care of newborns, as well as establishing a regional network for newborn health. Dr Thinley advocated for expanding this network to include birth defects prevention.

Ms Anuradha Gupta, Additional Secretary and Director of the National Rural Health Mission, Ministry of Health and Family Welfare, India, formally released the standard treatment guidelines for common neonatal conditions in small hospitals. Ms Gupta urged a multi-pronged attack to address neonatal mortality, which she described as the "Achilles heel" of under-five mortality. In India, home-based newborn care has been started through the Accredited Social Health Activist (ASHA) programme, and through increased access to facility-based newborn care. Another important factor in this multipronged approach is addressing the social determinants of health, such as clean water, basic sanitation, nutrition and personal hygiene.

Ms Gupta noted that there were a large number of birth defects and the survivors are a burden on the family, the community and society. Thus it is important to look beyond mortality. A "verticalization" of efforts to prevent and control birth defects was considered useful. Moreover, issues must not be looked at in isolation, but instead as pieces of the whole puzzle. India's new national child health screening initiative was briefly described, which addresses the "four Ds": defects, deficiencies, diseases and developmental disorders (including disabilities). This new initiative proposes to undertake comprehensive screening for children up to 18 years of age, twice a year, performed by Anganwadi (village health-care centre) workers and schools, supplemented by mobile teams of doctors and nurses, and backed by a strong referral system. The screening programme was initiated in the state of Maharashtra.

Ms Gupta closed by stating that "for dreams to come true, we need to wake up and work very hard."

Dr Ashok Deorari, AIIMS, proposed a vote of thanks to WHO, CDC, and all the experts, delegates and partners for making this important meeting possible.

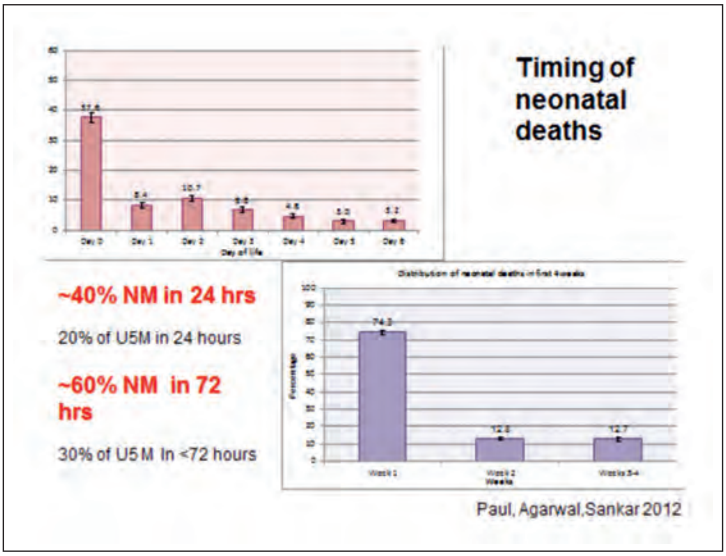
3. Setting the stage

Chairpersons: Ms Karen Codling, Flour Fortification Initiative and Dr VK Paul, AIIMS

3.1 Emerging paradigm of newborn health

Dr VK Paul, AIIMS, began the session by noting the 33% global reduction in neonatal mortality since 1990. While neonatal mortality has declined in every region, sub-Saharan Africa and South Asia has not done as well as other regions (Figure 1). India has the largest neonatal mortality burden in terms of population size and rate, followed by Nigeria, Pakistan, and the People's Republic of China. Bangladesh had been a "break-out" nation because of its rapid reduction in neonatal deaths.

In India, about 75% of neonatal deaths occur during the first week, nearly 13% by the second week and the remaining deaths after two weeks. Of all newborn deaths,



Timing of neonatal deaths

~40% NM in 24 hrs

20% of U5M in 24 hours

~60% NM in 72 hrs

30% of U5M In <72 hours

Paul, Agarwal,Sankar 2012

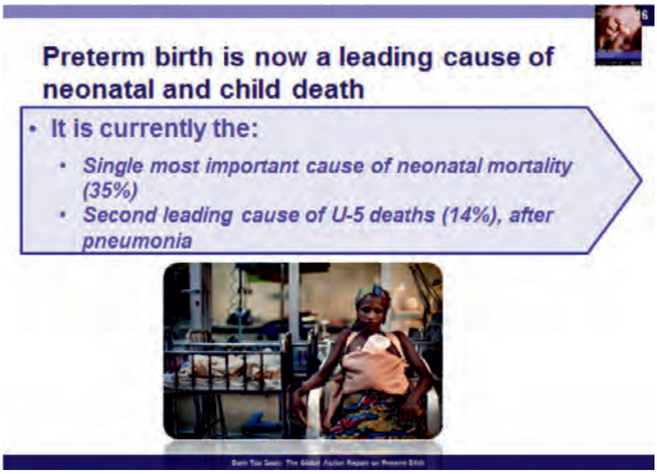
37% occur on the first day and 60% occur during the first three days of life. There has been practically no change in the first week mortality data in India, a trend that is seen all over the world, despite increased institutional deliveries.

Dr Paul outlined new ways to make headway in reducing neonatal mortality. First, for institutional deliveries, improvements must be made in special care of newborns, skilled care of labour and delivery, and in increasing breastfeeding. Second, the uptake and quality of home care must also improve, and the significant inequity in home-based care addressed, such as the imbalance in care given to newborn girls and boys in India.

He closed by welcoming this opportunity of Networking in the Region to build on the efforts to reduce neonatal mortality. Coming together of the birth defects experts and champions would contribute in raising the momentum further.

3.2 Addressing preterm births: global movement

Dr Chris Howson provided a briefing on the March of Dimes and WHO report, *Born Too Soon: The Global Action Report on Preterm Birth*. The publication, released in May 2012, provides the first ever national, regional and global estimates of preterm birth, defined as born alive before 37 weeks of pregnancy. Dr Howson noted that preterm



Preterm birth is now a leading cause of neonatal and child death

- It is currently the:
  - *Single most important cause of neonatal mortality (35%)*
  - *Second leading cause of U-5 deaths (14%), after pneumonia*

birth was a hidden and neglected problem within the issue of perinatal mortality, which is underscored in the report by the comparable country estimates. Addressing preterm birth would contribute significantly to reaching Millennium Development Goal 4. The Report shows that rapid change is possible and proposes actions for policy, programmes and research.

The five main findings of the report are as follows:

- First, 15 million babies – more than 1 in 10 – are born too soon every year, and over 1 million children die each year due to complications of preterm birth. Many survivors face a lifetime of disability, including learning disabilities and visual and hearing problems.
- Second, rates of preterm birth are rising in almost all countries. Prematurity is the leading cause of newborn deaths (babies in the first four weeks of life) and the second leading cause of death after pneumonia in children under the age of five.
- Third, prevention of preterm birth must be accelerated through family planning and increased empowerment of women, especially adolescents. Improved quality of care before, between and during pregnancy can also help to reduce preterm birth rates.
- Fourth, premature babies can be saved now with feasible, cost-effective care, and deaths can be reduced by over three quarters, even without the availability of neonatal intensive care.
- Fifth, everyone has a role to play: Dr Howson highlighted the *Every Woman Every Child* effort, led by United Nations Secretary-General Ban Ki-moon that provides a framework to coordinate action and ensure accountability.

Future directions for the March of Dimes to support birth defects prevention include: support for the Global Newborn Action Plan; World Prematurity Day (17 November); the World Prematurity Network; research on estimates of economic costs of prematurity in Latin America; uptake of Caesarean section rates; and engagement of scientists around the discovery and research agenda.

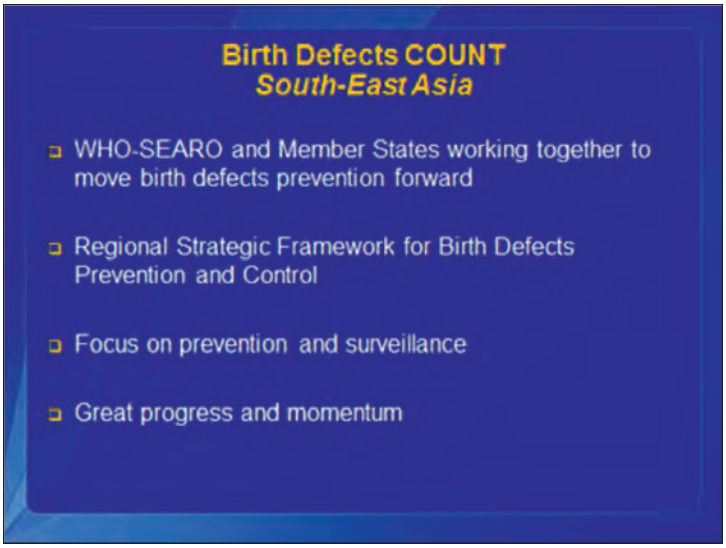
Born Too Soon: 5 main findings

1. **15 million babies are born too soon every year**
   - 1.1 million babies die annually from complications due to prematurity
   - Significant disability for many survivors
2. **Preterm birth rates are rising**
3. **Prevention of preterm birth must be accelerated**
4. **Premature babies can be saved now with feasible, cost-effective care**
5. **Everyone has a role to play to meet the targets set**

3.3 Prevention of birth defects: CDC's global efforts

Dr Joseph Sniezek reported on the CDC initiative, *Birth Defects Count* –a global initiative with a principal focus on eliminating folic acid-preventable neural tube defects (NTDs). These are serious birth defects of the spine and brain, and are a significant cause of infant mortality and childhood morbidity worldwide. Globally there are more than 300 000 babies born with NTDs each year. CDC has made a significant contribution to NTDs prevention over the past two decades and led the way in promoting that every woman who could become pregnant should consume 400 μg of folic acid daily to prevent neural tube defects. Dr Sniezek discussed CDC's work with WHO and others to establish a global policy to support and advance global and country-level fortification efforts and other interventions, and fill scientific and technical gaps by engaging in strategic partnerships.

One focus of CDC work is to help strengthen surveillance systems that can accurately monitor the prevalence of NTDs and other observable birth defects, work that has been started in partnership with SEARO. He reiterated CDC support for the Strategic Framework on the Prevention and Control of Birth Defects in the SEAR, and stressed the need to integrate birth defects activities with the prominent programmes that are already "on the ground" in countries.



Birth Defects COUNT
South-East Asia

- WHO-SEARO and Member States working together to move birth defects prevention forward
- Regional Strategic Framework for Birth Defects Prevention and Control
- Focus on prevention and surveillance
- Great progress and momentum

3.4 Regional initiatives to strengthen newborn health and prevent birth defects

Dr Neena Raina, SEARO, stated that neonatal mortality remained high in 6 of the 11 Member States in the SEAR. She added that health inequity was a major problem, citing that lower-income mothers are more likely to lose their babies and that education is a very strong determinant in the outcome. In addition, coverage of life-saving interventions for newborn and child health across the continuum-of-care is low, e.g., the levels of early breastfeeding, caring for low-birth-weight babies and treatment of diarrhoea.

Dr Raina summarized the tools available to strengthen newborn care, saying that as improvements occur and deaths due to asphyxia and infections decline, birth defects will come to the forefront. Birth defects, asphyxia and premature births contribute 35–55% of neonatal mortality. An unknown area is the contribution of fetal deaths and stillbirths.

The "window of opportunity" to prevent birth defects is preconception care, with pre-pregnancy interventions. Dr Raina outlined the meetings that had been conducted under the SEARO birth defects prevention initiative and reported that a birth defects surveillance manual, atlas and training package were under development. Birth defects prevention networks are being developed at national level in Bangladesh, India, Myanmar, Nepal and Thailand, which should now be supported by a new regional network.

Strengthening Newborn Health in SEAR

- **Home based newborn care:** Introduction of home visits for providing postnatal care
- **Facility based newborn care:**
  - E-Courses: WHOCC
    - ENCC
    - Sick Newborn Care
  - Standard Treatment Protocols
- **Include 'N' in IMCI**
- **Neonatal-perinatal database**

SEARO progress so far...

- Expert Group Meeting on prevention of birth defects in November 2011
- Regional Programme Managers Meeting on birth defects meeting: Mar 2012
- Birth Defects Surveillance meeting: April 2012
- Regional Situation Analysis on Birth defects
- Regional Strategy for prevention of birth defects

She closed by stating that the key challenges for birth defects prevention in the Region are to strengthen and expand vital registration, scale-up preventive strategies, screening and referral, build capacity and support networks.

4. Strategies for prevention and control of birth defects

Chairpersons: Professor Mohammod Shahidullah, Bangabandhu Sheikh Mujib Medical University, Bangladesh and Dr K Pappu, UN Office for Project Services: Norway—India Partnership Initiative

4.1 Prevention of birth defects and maternal risk factors

Dr Joseph Sniezek, CDC, in discussing maternal risk factors for birth defects, noted the efficacy of folic acid in the reduction of the incidence of neural tube defects. Evidence for this has been available since the 1980s, but has been slow to put into practice for food fortification. Examples of food fortification in Chile, Costa Rica and the USA were presented. Dr Sniezek also discussed rubella as a maternal risk factor, noting the high burden of rubella in the SEAR.

Addressing Maternal Risk Factors

- Give protection
  - Folic acid
  - Vitamin B12
  - Rubella sero-negativity
- Manage conditions
  - Diabetes
  - Obesity
- Avoid teratogens
  - Alcohol use
  - Medication use
  - Smoking

9

Give Protection
Folic Acid Supplementation/Fortification

Folic Acid

- Significantly reduces the occurrence of neural tube defects
- **U.S. Public Health Service Recommendation**
  - Consume 400 micrograms of synthetic folic acid every day for the prevention of neural tube defects and possible reduction of risk for cleft lip/palate and heart defects

10

Diabetes and obesity are significant problems and their rates are increasing, especially where there is rapid economic development, although very little data are available on the prevalence of these conditions in women of reproductive age. Alcohol use is also an important known risk factor for which screening is quite effective, but efforts are needed to reduce the consumption of alcohol in women of reproductive age. Prescriptions for pregnant women need to be reviewed as the risks from medication are not well known and it is important to guard against their unnecessary use.

Dr Sniezek noted that smoking, including second-hand smoking, is also a known risk factor in pregnancy associated with the incidence of birth defects. Global tobacco surveys show that in many countries, smoking rates in girls are similar to those in boys.

4.2 Prevention and control of birth defects in the SEAR: Strategic Framework (2013–2017)

Dr Rajesh Mehta, SEARO, provided a brief on the Regional Strategic Framework on Birth Defects Prevention and Control. The Strategic Framework has been developed in consultation with the Member States based on the recommendations made by the World Health Assembly. The principal goal is to reduce preventable birth defects, with specific targets to reduce by 2017 folic acid-preventable neural tube defects by 35%, reduce thalassaemia births by 50%, reduce congenital rubella and eliminate congenital syphilis.

The Framework’s five strategic directions are:

Prevention and Control
of Birth Defects
in South-East Asia Region

Strategic Framework
(2013–2017)

World Health
Organization

- to establish or strengthen national policies and programmes for birth defects prevention and control;
- to develop and strengthen national birth defects surveillance, monitoring and evaluation mechanisms;
- to integrate birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant mechanisms;
- to expand and strengthen national capacity for implementation of birth defects prevention and control programmes; and
- to develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

In addition, the Framework suggests steps for national implementation and monitoring indicators for the strategic directions.

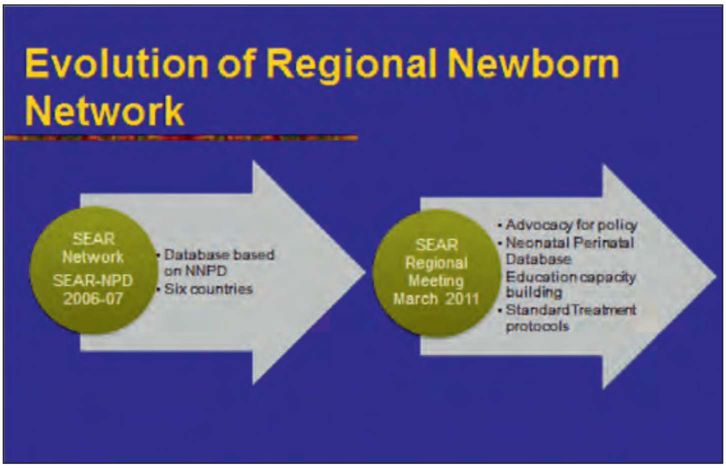
Dr Mehta said that in implementing birth defects prevention strategies a “life-course” and “healthy transitions” approach should be adopted. Ideal healthy transitions during adolescence include a weekly programme of adequate folic acid supplementation and daily folic acid in the periconceptional period. There is a need to repackage services for adolescents who are transiting into adulthood and entering the reproductive cycle. The importance of networking and partnerships was emphasized, as there is a need to find more resources for birth defects prevention.

5. Regional and national networks

5.1 Progress of the Regional Network on Newborn Health

Dr Ashok Deorari, AIIMS, described the Regional Network on Newborn Health and the proposal to integrate birth defects-related activities. The vision for the AIIMS WHO Collaborating Centre is to support centres to create neonatal-perinatal databases, and to enhance the capacity of such centres in the Member States. The Regional Network on Newborn Health initially had six members that are now creating networks within their countries. Dr Deorari said that facility-based care was the cornerstone of the networks.

He described the numerous advantages of the neonatal-perinatal database established at AIIMS in 1995 with several centres in India, and later expanded to centres of excellence in six SEAR countries. The biggest challenge was to sustain the motivation of the partners to sustain the network.



Evolution of Regional Newborn Network

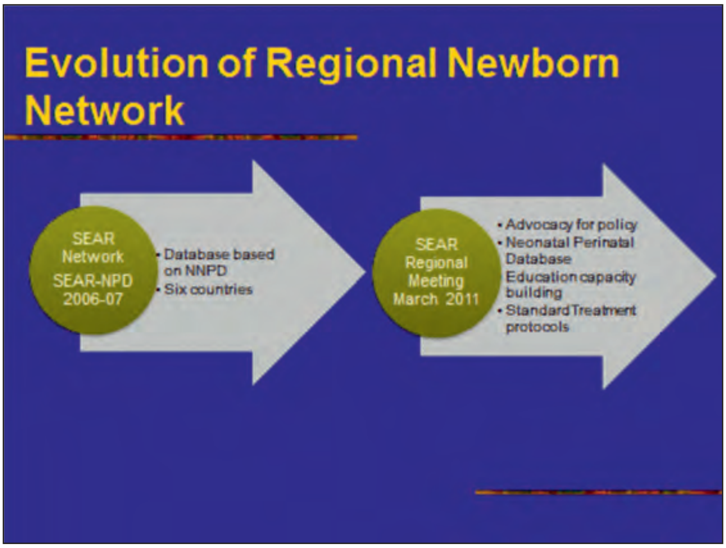
SEAR Network
SEAR-NPD
2006-07

- Database based on NNPD
- Six countries

SEAR Regional Meeting March 2011

- Advocacy for policy
- Neonatal Perinatal Database
  Education capacity building
- Standard Treatment protocols

Dr Deorari also explained the role of the WHO Collaborating Centre and the Regional Network in capacity building for newborn care. He described the steps taken to move from classroom training to an interactive/e-learning model, and informed participants that an e-learning tool had been developed. The digitalized courses, comprising lessons and evidence-based protocols, can be an effective way to strengthen newborn care and improve the quality of care in hospitals in general.



Evolution of Regional Newborn Network

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SEAR Regional Meeting March 2011

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- Neonatal Perinatal Database
- Education capacity building
- Standard Treatment protocols

In summary, there was an urgent need to create a database for birth defects, which Dr Deorari proposed could be integrated into the existing neonatal-perinatal database.

5.2 Progress of national networks on newborn health

Three countries, Bangladesh, Myanmar and Nepal have established networks of institutions and have started collecting data for Neonatal-Perinatal Database. They shared progress during the meeting.

The other countries participating in the meeting also shared the present status of activities related to neonatal-perinatal database and interest in developing national networks for this purpose.

Bhutan shared that they have maternal and neonatal death review committees in all 20 districts but there is no inclusion of morbidity.

Maldives informed that network activities have been initiated in 2011, which currently consists of the National Hospital in Male, one private hospital in Male and five regional hospitals that began data collection with WHO support. However the system has to be strengthened and standardized.

Sri Lanka reported that they have a good health information system in the country. Neonatal morbidity and mortality figures are provided by the hospital information system. There is no specific system for birth defects surveillance at the moment.

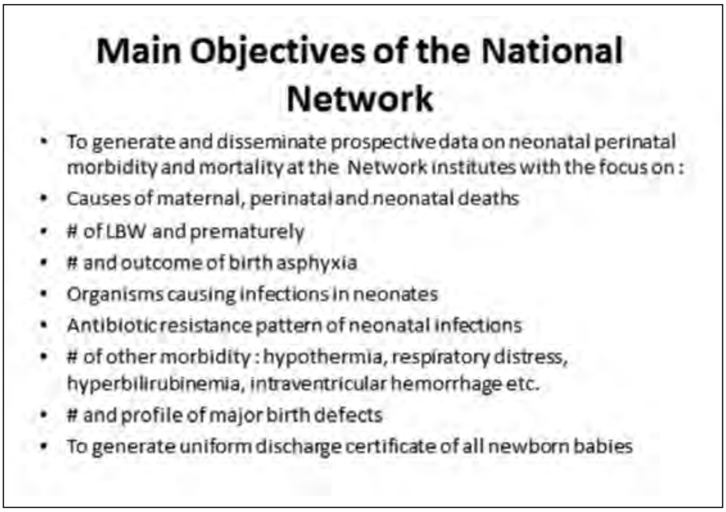
Participants from Thailand conveyed that there is a national database that includes information on children but none on the health and status of the mother. The information is at present used for perinatal mortality. Birth defects registry has been initiated for prioritized birth defects.

Bangladesh

Professor Mohammod Shahidullah reported that Bangladesh was on track to meet the MDG4 and had reduced under-five mortality by 60% in the last 10 years. In Bangladesh, preterm births and complications are responsible for the majority of deaths in the neonatal period. Bangladesh has established a national network with 14 centres.

In order to make it sustainable it has been linked to national reporting and dissemination activities, and extensive training has been conducted. The intention is to develop data on birth defects, and partnerships with the United Nations Children's Fund (UNICEF), International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) and Save the Children. WHO has promised support for 14 medical colleges and logistics support for the programmes. Another challenge is the limitation of information technology in Bangladesh.

TOT on NNPD in Bangladesh
On 6-11 April, 2013



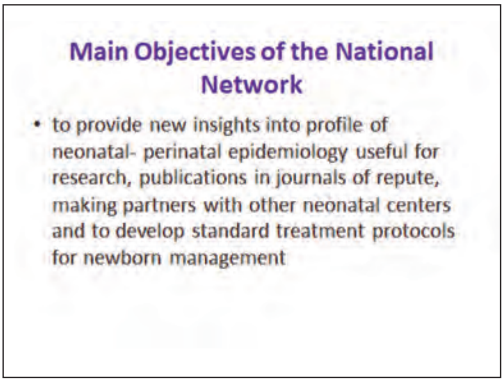
Main Objectives of the National Network

- To generate and disseminate prospective data on neonatal perinatal morbidity and mortality at the Network institutes with the focus on :
- Causes of maternal, perinatal and neonatal deaths
- # of LBW and prematurely
- # and outcome of birth asphyxia
- Organisms causing infections in neonates
- Antibiotic resistance pattern of neonatal infections
- # of other morbidity : hypothermia, respiratory distress, hyperbilirubinemia, intraventricular hemorrhage etc.
- # and profile of major birth defects
- To generate uniform discharge certificate of all newborn babies

Myanmar

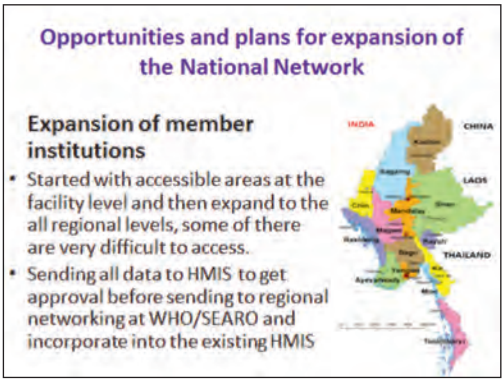
Dr Hla Mayt Nwe explained that Myanmar was part of the Regional Network on Newborn Health, with the Central Women's Hospital in Yangon as the nodal centre and neonatal hospitals at the apex institutions and regional hospitals. The network partners are the Health Management Information System (HMIS) and the Ministry of Health as well as the WHO Collaborating Centre, AIIMS. There is a plan to expand the network. Member institutions collect and share data in a standard format, and undertake any follow-up actions that might be necessary.

The main challenges include a lack of sustained electrical power for infrastructure like computers; irregular updates of the database due to the clinical responsibilities of the doctors and health workers; difficulties in collecting and analysing data on standard formats; and technical support and resource mobilization.



Main Objectives of the National Network

- to provide new insights into profile of neonatal- perinatal epidemiology useful for research, publications in journals of repute, making partners with other neonatal centers and to develop standard treatment protocols for newborn management



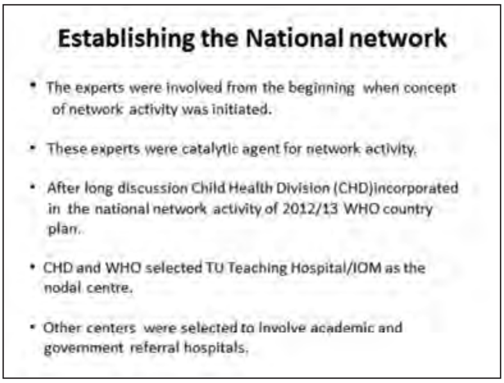
Opportunities and plans for expansion of the National Network

Expansion of member institutions

- Started with accessible areas at the facility level and then expand to the all regional levels, some of there are very difficult to access.
- Sending all data to HMIS to get approval before sending to regional networking at WHO/SEARO and incorporate into the existing HMIS

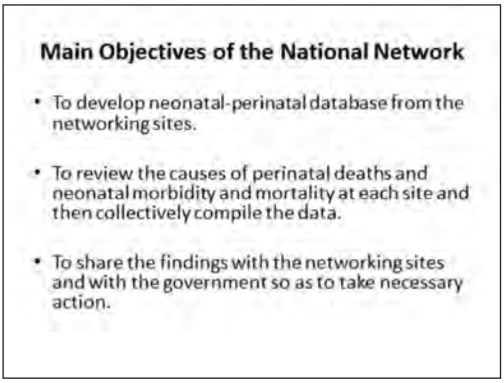
Nepal

Dr Laxman Shreshta reported the progress on the newborn health network in Nepal. The network has six hospitals as member institutions. Support has been provided by AIIMS, the WHO Collaborating Centre, with focus on the neonatal-perinatal database. The system is similar to the national network in Bangladesh. The main challenges are uniformity in criteria for admission for sick newborns and in establishing the cause of death.



Establishing the National network

- The experts were involved from the beginning when concept of network activity was initiated.
- These experts were catalytic agent for network activity.
- After long discussion Child Health Division (CHD)incorporated in the national network activity of 2012/13 WHO country plan.
- CHD and WHO selected TU Teaching Hospital/IOM as the nodal centre.
- Other centers were selected to involve academic and government referral hospitals.



Main Objectives of the National Network

- To develop neonatal-perinatal database from the networking sites.
- To review the causes of perinatal deaths and neonatal morbidity and mortality at each site and then collectively compile the data.
- To share the findings with the networking sites and with the government so as to take necessary action.

5.3 Perspectives for the future

Dr Neena Raina noted that the foundations had been laid for birth defects prevention efforts, including surveillance, to be integrated into established networks and programmes. The priority is to have standardized, comparable data that are reported regularly. She requested participants to develop and agree on a set of specific birth defects variables, with initial focus on visible, structural defects. Dr Raina emphasized that birth defects surveillance could start with existing hospital-based systems, that capacity building was needed to improve the quality of care and that focus should be on data needed for the Region's priority preventive strategies.

6. Database for newborn health and birth defects

Chairpersons: Dr Chris Howson, March of Dimes and Dr Ashok Deorari, AIIMS

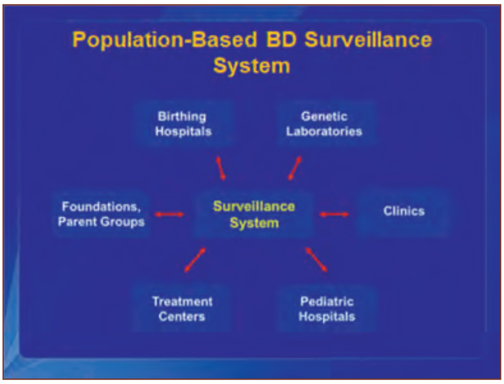
6.1 Surveillance for birth defects: principles

Dr Joe Sniezek, CDC, defined public health surveillance as the ongoing and systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice. He also emphasized that dissemination and use of public health surveillance data is essential. He then outlined the role of surveillance in the public health framework for prevention and health promotion, which can be thought of as a cycle of conducting surveillance, analysing the data through epidemiological studies, and then developing policies and programmes.

The primary purposes of birth defects surveillance are to measure the burden and monitor trends, identify disparities by maternal characteristics, identify clusters, inform public health and health-care policies, and generate hypotheses for epidemiologic and prevention research. Surveillance is also critical to creating the social and political will to address birth defects prevention; without solid data on the burden of birth defects, the issue is invisible to the public and to policy-makers.

Dr Sniezek discussed the numerators and denominators involved in birth defects surveillance. For the numerator, the definitional issues are which cases to include or exclude, and at what age defects are diagnosed. The objective is to identify all cases in target populations that meet case definitions, while dealing with the problem of observed true cases versus observed false-positive cases. He then detailed issues around active versus passive case ascertainment: there has to be a balance between active and passive systems, and single versus multiple data sources – the latter can be essential to ensuring quality of data

Approaches to defining the denominator for birth defects surveillance are essentially a choice between hospital- and population-based. Hospital-based surveillance is more convenient and less resource intensive than population-based surveillance, which makes the former the more likely starting point for countries. More important than data collection is their analysis and use for decision-making; this requires dissemination of the data. The continuum of care approach starts with passive data collection, with the quality of dataimproving in line with the intensity of active collection of data.



Population-Based BD Surveillance System

Birthing Hospitals

Genetic Laboratories

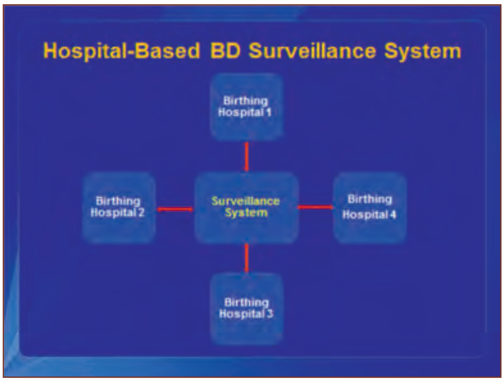
Foundations, Parent Groups

Surveillance System

Clinics

Treatment Centers

Pediatric Hospitals



Hospital-Based BD Surveillance System

Birthing Hospital 1

Birthing Hospital 2

Surveillance System

Birthing Hospital 4

Birthing Hospital 3

Dr Sniezek suggested the following nine steps to developing a birth defects surveillance system:

(1) Engage your stakeholders

(2) Establish purposes

(3) Develop case definitions

(4) Determine sources of data or data collection mechanisms

(5) Develop data collection instruments

(6) Field test methods

(7) Develop and validate analytic approach

(8) Plan dissemination early; and

(9) Ensure use of analysis and interpretation.

The presentation concluded with a history of birth defects surveillance in the USA since 1926, and a discussion of CDC's role in supporting national birth defects surveillance work.

6.2 Regional–national networks for birth defects: conceptual framework

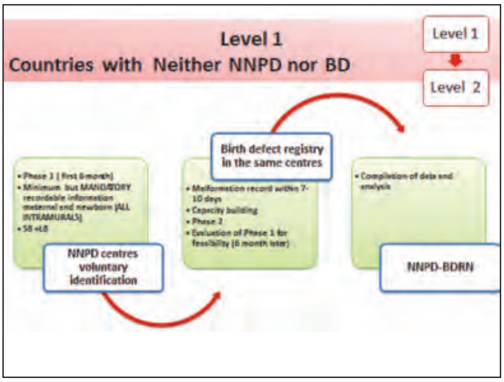
Drs Madhulika Kabra and Neerja Gupta of AIIMS presented the conceptual framework for birth defects networks. Dr Kabra noted that the goal of the South-East Asia network was to develop and implement a birth surveillance system that promotes early and accurate identification of birth defects and facilitate prevention, planning and service delivery. The primary objectives of such networks are to: facilitate regular and systematic recording of birth defects in a sustainable, standardized and efficient way; identify the magnitude and profile of the birth defects; identify risk factors; create awareness among the public, health professionals and policy-makers using simple teaching tools; assist policy-makers in implementing evidence-based advocacy and prevention programmes; and integrating birth defects within existing health-care systems. Secondary and tertiary objectives were also discussed.

There are several steps to establish networks. First, establish a neonatal-perinatal database and birth defects database and agree on the minimum number of variables. Next, there should be voluntary enrolment to build the national and regional networks, regular monitoring to address quality assurance issues and capacity building. This should be followed by activities to support information, education and communication, implementation of preventive strategies and integration into national programmes. As parallel steps, each country should identify centres for voluntary participation and Nodal Persons, which has already been done in some countries. Finally, referral centres for service support within the country/region should be identified along with existing resources and plans for generating extra resources.

Dr Kabra discussed the proposed surveillance methodology for the networks. She proposed that hospital-based surveillance is used with age inclusion criteria being live births until discharge, stillbirths after 28 weeks of gestation, and the type being externally visible structural defects, i.e. congenital malformations of the nervous system, cleft lip and cleft palate, congenital malformations of genital organs, congenital malformations and deformations of the musculoskeletal system, anorectal malformations, tracheoesophageal fistula and deafness. Tools for data collection and analysis were suggested, as well as the needed manpower and financial resources, information, education and communication activities and training.

Dr Gupta presented a graphical representation of the three levels of the proposed networks – state/district, national and regional – all of which have levels of complexity.

She explained the potential two-way communication with the region and cross communication within the Member countries. The key message was that the project should start small and then be constantly enlarged. The short-term goal of the logic model of the networks was uniform, region-wide implementation of the surveillance programme and instituting secondary prevention by counselling and early detection, while the long-term goals were to reduce the prevalence of preventable malformations, develop policies for food fortification, improve need-based infrastructure to manage birth defects, and conduct research. The ultimate impact of the networks is an improved quality of life of affected individuals and reduced under-five mortality.



Level 1
Countries with Neither NNPD nor BD

Level 1
Level 2

- Phase 1 (first 6 month)
- Minimum but MANDATORY recordable information maternal and newborn (ALL INTRAMURALS)
- SB +LB

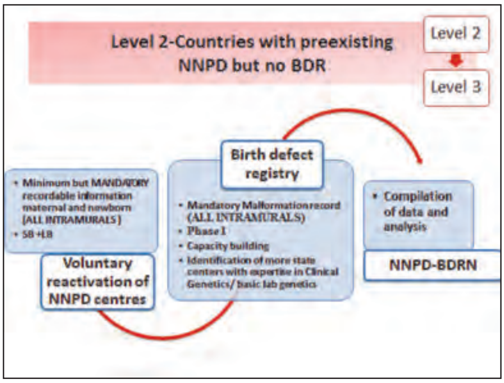
NNPD centres voluntary identification

Birth defect registry in the same centres

- Malformation record within 7-10 days
- Capacity building
- Phase 2
- Evaluation of Phase 1 for feasibility (6 month later)

- Compilation of data and analysis

NNPD-BDRN



Level 2-Countries with preexisting NNPD but no BDR

Level 2
Level 3

- Minimum but MANDATORY recordable information maternal and newborn (ALL INTRAMURALS)
- SB +LB

Voluntary reactivation of NNPD centres

Birth defect registry

- Mandatory Malformation record (ALL INTRAMURALS)
- Phase I
- Capacity building
- Identification of more state centers with expertise in Clinical Genetics/ basic lab genetics

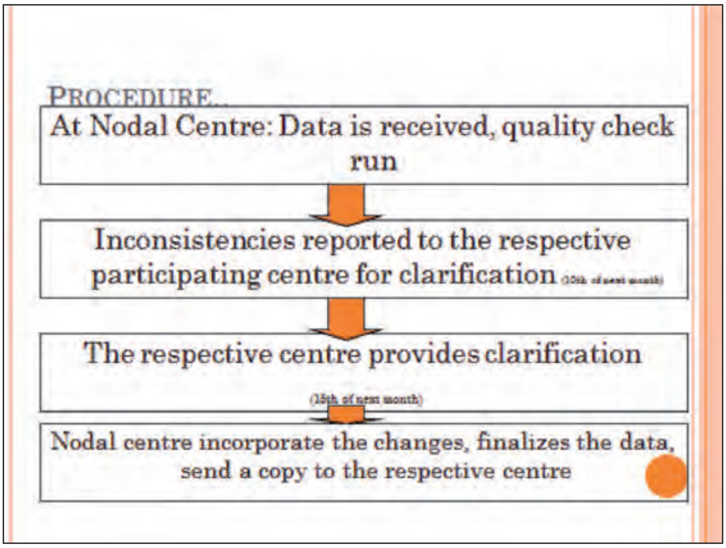
- Compilation of data and analysis

NNPD-BDRN

Dr Howson, March of Dimes, noted that the guiding principle of the Regional–National Networks for Birth Defects might be to “Make it as simple as possible, but no simpler.”

6.3 Neonatal-perinatal database: available models

Dr Ramesh Agarwal, AIIMS, presented India’s Neonatal-Perinatal Database (NNPD) as a model. The comprehensive database for tertiary level hospitals covers in-born babies (intramural births), stillbirths and out-born babies (extramural births), using Microsoft Access® software. This database has been used in selected centres in six countries in the Region, called the SEAR database, with an option to create a discharge summary. Standard definitions, infrastructure (computers) and dedicated trained staff are required. There are four different forms: Form A for inborn babies, Form B for stillbirths, Form C for outborn babies, and Form D for birth defects. Once data are collected using the standardized forms and checked by the designated staff, they are entered into the NNPD software. The data is quality controlled at the nodal centre, and clarification sought from the participating centre in the case of any inconsistency. The pooled data is then analysed and the summary report shared with all the participating centres. The NNPD database allows several types of analysis such as descriptive analyses, risk factors of mortality outcome, risk prediction models as well as growth charts and country-wise comparisons. Monitoring is the crucial issue in the database. Thus, for quality assurance at least 30 minutes are required daily. The database has been customized in more than 100 hospitals in the country as per the local needs and feasibility.



PROCEDURE..

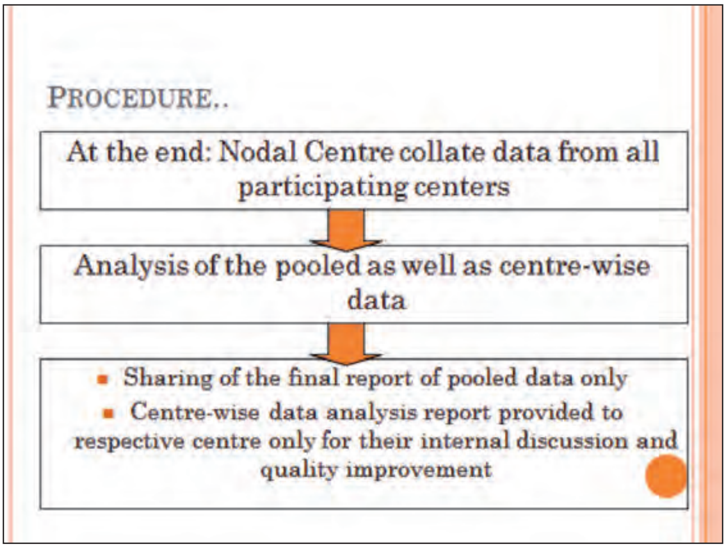
At Nodal Centre: Data is received, quality check run

Inconsistencies reported to the respective participating centre for clarification (10th of next month)

The respective centre provides clarification

(15th of next month)

Nodal centre incorporate the changes, finalizes the data, send a copy to the respective centre



PROCEDURE..

At the end: Nodal Centre collate data from all participating centers

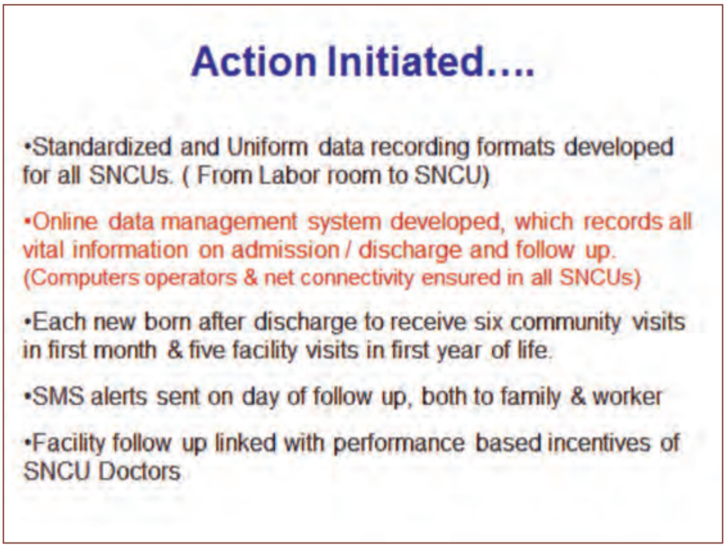
Analysis of the pooled as well as centre-wise data

- Sharing of the final report of pooled data only
- Centre-wise data analysis report provided to respective centre only for their internal discussion and quality improvement

UNICEF: Special Newborn Care Units experience

Dr Gagan Gupta of UNICEF presented the data management of the special newborn care units (SNCU), which has been operationalized in Madhya Pradesh State, India, and accepted by the Ministry of Health for national scaling up. The SCNU system was established in 2007 as one approach to address the infant mortality rate in Madhya Pradesh, which was the highest in India, at 72 per 1000 births at that time. Today, 42 SCNUs are operational, with a concomitant increase in hospital admissions.

A study by Guna and Shivpuri on the treatment outcome of babies admitted in SCNUs up to the age of 1 year revealed that survival rate was 90%. From the total deaths of 255 babies, two thirds occurred in the first month of discharge from the units. Mortality was higher in babies with admission weight <2 kg. Thus, standardized data recording and a follow-up system for SCNUs were developed and a secure online data management system established to record all vital information on admission and discharge as well as follow-up until the age of 1 year. Log-in and entering data can be done at the district level, while at the state and national levels only review of data is permitted. The database allows single and/or multiple diagnosis based on ICD 10 codes. There are provisions for generating analysed data in pdf format. The application has also been rolled out in the state of Haryana.



Action Initiated....

- Standardized and Uniform data recording formats developed for all SNCUs. (From Labor room to SNCU)
- Online data management system developed, which records all vital information on admission / discharge and follow up. (Computers operators & net connectivity ensured in all SNCUs)
- Each new born after discharge to receive six community visits in first month & five facility visits in first year of life.
- SMS alerts sent on day of follow up, both to family & worker
- Facility follow up linked with performance based incentives of SNCU Doctors

SNCU Data Management & Follow-up Tracking System

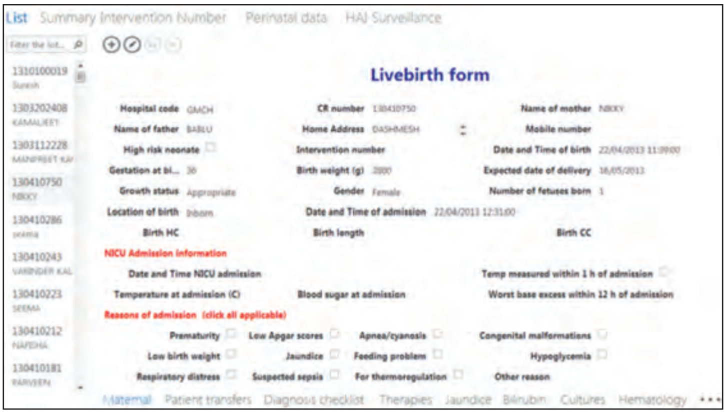
Joint effort of Government of M.P. & UNICEF under NRHM

Special care for newborns
Giving chances to life...

Website Created & Maintained by NCS Pvt. Ltd. Indore Under Guidance of **Govt. of MP, NRHM** and UNICEF

Web-based database

Dr Deepak Chawla of the Government Medical College, India presented the web-based neonatal and perinatal database. He explained the advantages and disadvantages of the tool the need for the web-based version. Various Microsoft Access® forms have been used to capture data on high-risk cases, including live births, stillbirths and birth defects forms. It is possible to include quality indicators and to upload the clinical photograph on the system.



Livebirth form

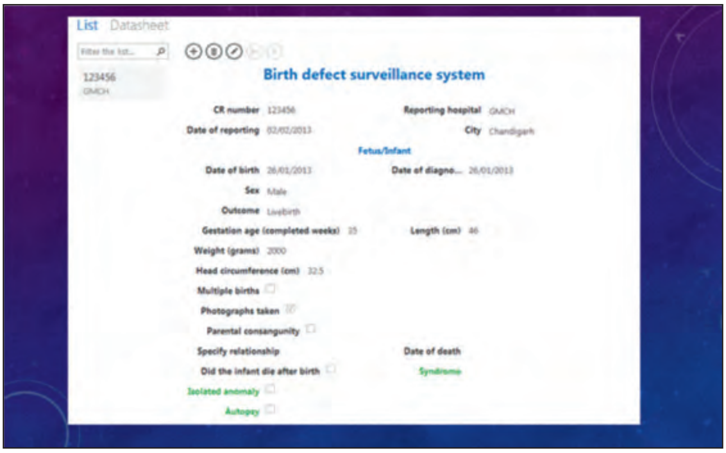
Hospital code GMCH
CR number 130410750
Name of mother NIKKY
Name of father BABLU
Home Address DASHMESH
Mobile number
High risk neonate ☐
Intervention number
Date and Time of birth 22/04/2013 11:39:00
Gestation at bi... 38
Birth weight (g) 2000
Expected date of delivery 16/05/2013
Growth status Appropriate
Gender Female
Number of fetuses born 1
Location of birth Inborn
Date and Time of admission 22/04/2013 12:31:00
Birth HC
Birth length
Birth CC

NICU Admission information

Date and Time NICU admission
Temp measured within 1 h of admission ☐
Temperature at admission (C)
Blood sugar at admission
Worst base excess within 12 h of admission

Reasons of admission (click all applicable)

Prematurity ☐ Low Apgar scores ☐ Apnea/cyanosis ☐ Congenital malformations ☐
Low birth weight ☐ Jaundice ☐ Feeding problem ☐ Hypoglycemia ☐
Respiratory distress ☐ Suspected sepsis ☐ For thermoregulation ☐ Other reason



Birth defect surveillance system

CR number 123456
Reporting hospital GMCH
Date of reporting 02/02/2013
City Chandigarh

Fetus/Infant

Date of birth 26/01/2013
Date of diagno... 26/01/2013
Sex Male
Outcome Livebirth
Gestation age (completed weeks) 35
Length (cm) 46
Weight (grams) 2000
Head circumference (cm) 32.5
Multiple births ☐
Photographs taken ☑
Parental consanguinity ☐
Specify relationship
Date of death
Did the infant die after birth ☐
Syndrome
Isolated anomaly ☐
Autopsy ☐

6.4 Group work on variables for an integrated database on newborn health and birth defects

Dr Rajesh Mehta, SEARO facilitated workgroups to develop recommendations for a standard form to collect variables for an integrated database on newborn health and birth defects. Variables on maternal health, live births, stillbirths and birth defects should be included.

Following the group discussions, Dr Ramesh Agarwal (India) reported that there was general consensus on variables to be collected for newborn health and birth defects. The variables will include data on two sets of risk factors, one core/mandatory and the other optional.

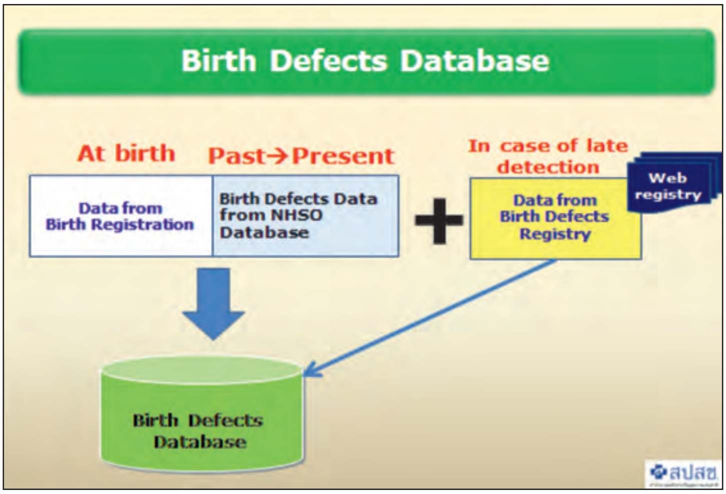
There was agreement within the plenary session on several future actions. In general, selection of variables should be guided by the prevalence of birth defects, and WHO guidelines. There will be further discussion with the network members on definitions and this will lead to standardization. The indicators should be minimized to what is doable, adding complexity as surveillance efforts and experience increase within the region. Parameters related to newborns were identified, although the single most common cause of death should be acknowledged. An Illness severity score is important to develop in the protocols. It is also important to select core study indicators, which serve two useful purposes: to strengthen the quality of care at the tertiary level; and to strengthen the national programmes.

7. Initiatives on strengthening newborn health and preventing birth defects

Chairpersons: Dr Joe Sniezek, CDC and Dr Dhammica Rowell, Sri Lanka

7.1 National Birth Defects Registry and Birth Defects Prevention Programme: Thailand

Dr Suthipong Pangkanon reported on the Thailand birth defect registry. Funded by UNICEF, the mandatory registry covers 96% of the population and uses the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD 10). Twenty birth defect conditions are screened through the registry, about half of which are detected in the first stage screening. There is now a proposed birth defects surveillance pilot project involving 20 hospitals, connected to counselling centres, which should be expanded to the entire country over the next five-years.



Birth Defects Database

At birth

Past → Present

In case of late detection

Data from Birth Registration

Birth Defects Data from NHSO Database

+

Data from Birth Defects Registry

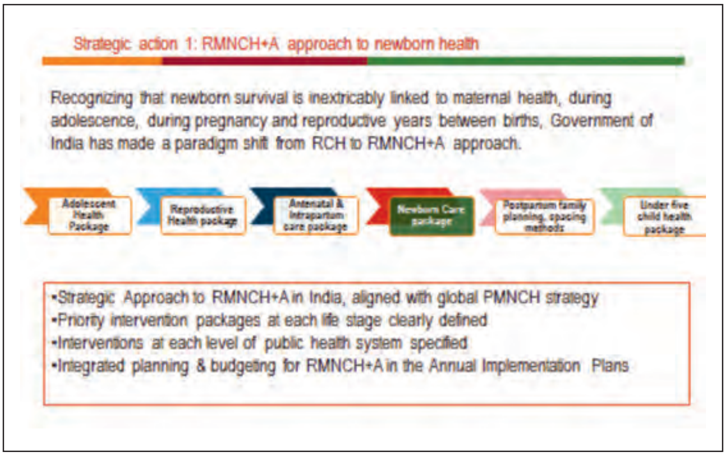
Web registry

Birth Defects Database

สปสช

7.2 National child health screening and early interventions: India

Dr Ajay Khera reported that in India neonatal mortality represents 70% of infant deaths. Recent data show a 2-point decline in neonatal mortality rates, with significant differentials between urban and rural rates as well as inter-state variations.



Strategic action 1: RMNCH+A approach to newborn health

Recognizing that newborn survival is inextricably linked to maternal health, during adolescence, during pregnancy and reproductive years between births, Government of India has made a paradigm shift from RCH to RMNCH+A approach.

Adolescent Health Package
Reproductive Health package
Antenatal & Intrapartum care package
Newborn Care package
Postpartum family planning, spacing methods
Under five child health package

- Strategic Approach to RMNCH+A in India, aligned with global PMNCH strategy
- Priority intervention packages at each life stage clearly defined
- Interventions at each level of public health system specified
- Integrated planning & budgeting for RMNCH+A in the Annual Implementation Plans

Insufficient attention has been given to date to the issue of birth defects, which are estimated to contribute around 10% of neonatal deaths.

Therefore the Government of India has undertaken several strategic actions. First, recognizing that newborn survival is inextricably linked to maternal and adolescent health, and throughout reproductive years, the Government made a paradigm shift from reproductive and child health (RCH) to the reproductive, maternal, neonatal, child health and adolescent health (RMNCH+A) approach. Second, it has instituted a new Newborn Continuum of Care approach that involves provision of newborn care corners (NBCC) at all delivery points, essential newborn care by ASHAs to all newborns delivered at home or a health facility and Sick Newborn Care Units at district hospitals and tertiary health facilities. Third, several actions are strengthening health systems for RMNCH+A at 184 high priority districts. Fourth, there are financial schemes and incentives linked to maternal and newborn care, including incentives to ASHAs and service guarantees for pregnant women and newborns. Fifth, there is a new national Child Health Screening initiative coupled with early intervention services. This initiative takes a systemic approach to early identification of the "four Ds": defects at birth, diseases, deficiencies and developmental delays, including disabilities in children 0 to 18 years of age. Dr Khera outlined the burden of the four Ds and the 30 health conditions to be screened and managed. All children will be screened twice a year during preschool age and once a year for older children. There will be an early intervention centre at the district level, and provisions for referral to the tertiary level. Sixth, India is undertaking a new National Iron Plus Initiative comprising a weekly iron and folic acid programme for adolescent boys and girls through school-based and community outreach approaches.

Strategic action 5 : Child Health Screening and Early Intervention Services

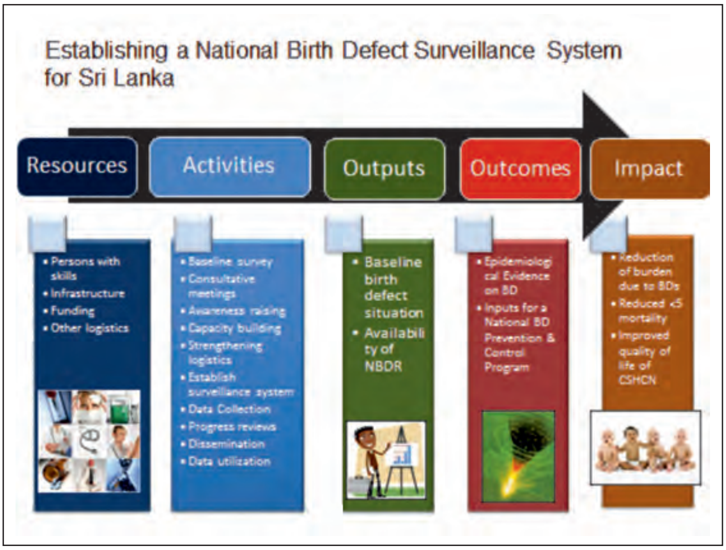
Rashtriya Bal Swasthya Karyakram

- Systemic approach to early identification of **4Ds: Defects at birth, Diseases, Deficiencies and Developmental delays including Disabilities** in **children 0 to 18 years of age.**
- Shift of focus to include Child Development as an agenda; overall aim is to work towards **Survival** & improving **Quality of life.**
- Existing **School health programme under NRHM** expanded to comprehensive screening for all children: Scheme is expected to cover more than 27 crore children in a phased manner.
- Initiative puts in place a comprehensive approach and ensures free management and treatment including surgical interventions at tertiary level through NRHM.

7.3 Integrating birth defects surveillance in the existing system: Sri Lanka

Dr Kapila Jayawardana summarized the new birth defects surveillance efforts being made by Sri Lanka. He reported that the surveillance system national focal point and a national technical working group have been established. Two districts, Colombo and Galle, will pilot the new system.

Several datasets are already available which will be integrated into the new system, including the perinatal death audit – universal in hospitals – field investigations of infant deaths (more than 90% of deaths are investigated), and congenital rubella syndrome (CRS) surveillance. In addition, doctors assure 100% coverage of newborn clinical screening. In Sri Lanka 99% of the deliveries take place in hospitals, with 94% in government hospitals and 5% by private doctors. Therefore in the initial phase the new web-based birth defects surveillance system will start in hospitals and then be



Establishing a National Birth Defect Surveillance System for Sri Lanka

Resources
- Persons with skills
- Infrastructure
- Funding
- Other logistics

Activities
- Baseline survey
- Consultative meetings
- Awareness raising
- Capacity building
- Strengthening logistics
- Establish surveillance system
- Data Collection
- Progress reviews
- Dissemination
- Data utilization

Outputs
- Baseline birth defect situation
- Availability of NBDR

Outcomes
- Epidemiological Evidence on BD
- Inputs for a National BD Prevention & Control Program

Impact
- Reduction of burden due to BDs
- Reduced <5 mortality
- Improved quality of life of CSHCN

extended to field-level work. Nine birth defects have been identified for screening. The primary strength of this initiative is the opportunity and ability for integration, but funding and capacity development will be challenges, as well as the ethical and legal issues around birth defects.

7.4 Strengthening facility-based newborn care in countries of the South Asian Association for Regional Corporation

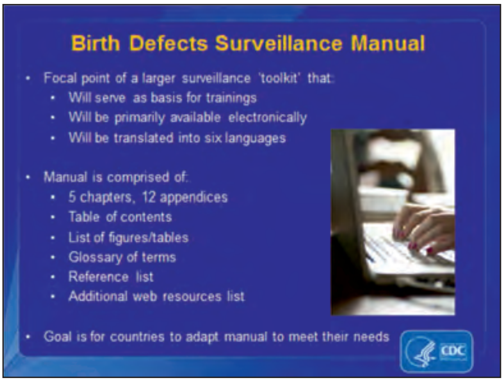
Dr RN Salhan, India, reported on the South Asian Association for Regional Corporation (SAARC) that includes 12 regional centres across Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka. The SAARC Project on Strengthening Maternal and Child Health including Immunization aims to improve the availability and adequacy of infrastructure and equipment at various districts and subdistrict levels in SAARC region, and to improve the maternal and child health skills of health-care providers. Dr Salhan outlined the project's various maternal and newborn care services, onsite assessment methodology and the training activities. He reported that so far the civil infrastructure activities have been completed in Bhutan, Maldives and Sri Lanka, as well as training-of-trainers, but other capacity-building exercises and some monitoring visits are overdue. The SAARC project emphasizes the need for community-based intervention to be linked with facility-based newborn care and a strong referral system, and the SAARC network can serve as model districts to provide a continuum of care.

8. Capacity building

Chairpersons: Dr Suthipong Pangkanon, Thailand and Dr San San Myint, Myanmar

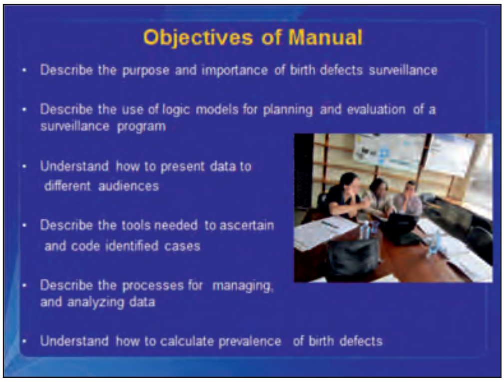
8.1 Birth Defects Surveillance Manual: Overview

Dr Joe Sniezek reported on the Birth Defects Surveillance Manual and the birth defects surveillance package being developed by CDC. The package includes a Training-of-the-Trainers curriculum, a Facilitator's Guide, a training package for data collectors, work books, a resource list and a birth defects photo atlas with videos and other resources provided on an online electronic platform. The Surveillance Manual is now being finalized by WHO. The other components are under development and should be available by the end of 2013. The Manual and the entire package will be made available to SEARO and all countries.



Birth Defects Surveillance Manual

- Focal point of a larger surveillance 'toolkit' that:
  - Will serve as basis for trainings
  - Will be primarily available electronically
  - Will be translated into six languages
- Manual is comprised of:
  - 5 chapters, 12 appendices
  - Table of contents
  - List of figures/tables
  - Glossary of terms
  - Reference list
  - Additional web resources list
- Goal is for countries to adapt manual to meet their needs



Objectives of Manual

- Describe the purpose and importance of birth defects surveillance
- Describe the use of logic models for planning and evaluation of a surveillance program
- Understand how to present data to different audiences
- Describe the tools needed to ascertain and code identified cases
- Describe the processes for managing, and analyzing data
- Understand how to calculate prevalence of birth defects

8.2 Communication strategy for birth defects prevention

Mr Burke Fishburn, CDC Consultant, discussed the Birth Defects Prevention Communications Toolkit which is being developed by CDC in collaboration with SEARO. He said that the Toolkit has evolved out of the Regional Strategic Framework for Birth Defects Prevention and Control, which had identified the need for specific communications strategies. The Toolkit is designed primarily to advocate the Strategic Framework as well as to provide support for national birth defects prevention plans. The kit will include an overall strategy, key messages and materials that can be adapted by countries, such as an executive summary of the Regional Strategic Framework, Frequently Asked Questions (FAQs) and at-a-glance fact sheets. There will also be a template for developing national communication plans and research guidance tools.

Birth defects prevention communication strategy in SEAR

- Strategic Framework for Prevention and Control of Birth Defects in South-East Asia Region (2013–2017)
  - Reduce the prevalence of birth defects in the South-East Asia Region in the next five years
- **Communication strategy supports:**
  - **Regional Framework**
  - → **Regional Birth Defects Network**
  - → **Support national plans**

SEARO Birth Defects Prevention Communication Toolkit

- Designed for grassroots advocates to promote birth defects prevention efforts
- Focused on advocacy for your national plan
- Now development (with CDC assistance)
- Components:
  - Core materials
  - Communication strategy
  - Key messages
  - Country customizable materials

8.3 E-training for newborn health care

Dr Ashok Deorari reported on the Online Training Orientation Programme for Newborns (ONTOP), the AIIMS sick newborn care e-learning course that is focused on doctors and nurses. for the work has evolved over the last 18 years into the ONTOP e-learning courses that have been rolled out in India and other Member countries and comprise both structured teaching, learning tools and webinars. The ONTOP webinars are available online through www.newbornwhocc.org.

Dr Anu Thukral (AIIMS) provided an online demonstration of the e-learning platform, which uses different techniques to expose students to several ways of learning. Dr Deorari noted the advantages of the ONTOP e-learning project. He said that the students are exposed to the best teachers in South-East Asia, best clinical practices are shared among participants and that e-learning makes the cross-cultural exchange of ideas possible. Once established, e-learning is an easy and cost effective tool.


NG ORIENTATION PROGRAMME IN ASIA

ONTOP

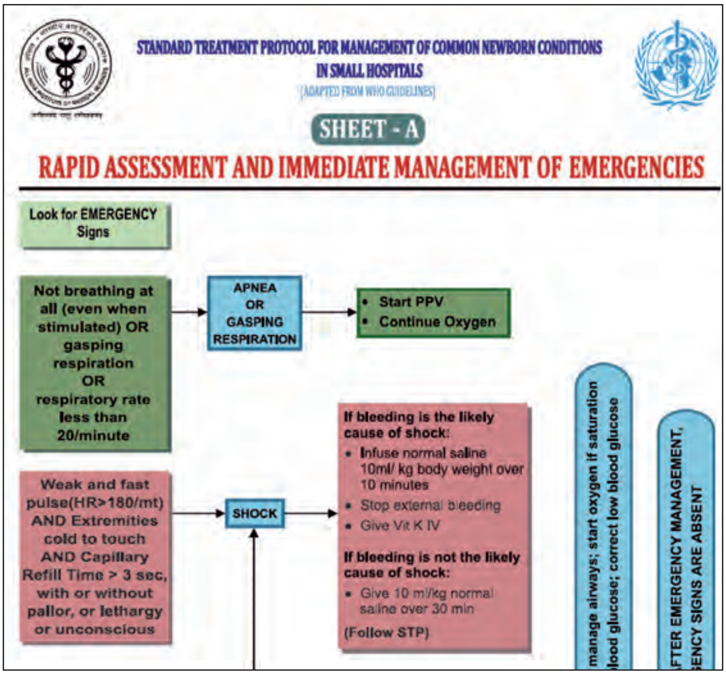
E-Learning Package
for
Doctors

Continuing Education
for
Best Practices & Skill Enhancement

E-Learning
on
Sick Newborn Care

8.4 Standard treatment protocols to manage newborn conditions in small hospitals

Dr Ashok Deorari (AIIMS) presented the standard treatment protocols (STPs) to manage common newborn conditions in small hospitals, which was identified as a need in Member States at the Regional meeting in March 2011. The Pink Book (Managing Newborn Problems) and Pocket Book published by WHO were adapted to be user-friendly.


STANDARD TREATMENT PROTOCOL FOR MANAGEMENT OF COMMON NEWBORN CONDITIONS
IN SMALL HOSPITALS
(ADAPTED FROM WHO GUIDELINES)

SHEET - A

RAPID ASSESSMENT AND IMMEDIATE MANAGEMENT OF EMERGENCIES

Look for EMERGENCY Signs

Not breathing at all (even when stimulated) OR gasping respiration OR respiratory rate less than 20/minute

APNEA OR GASPING RESPIRATION

- Start PPV
- Continue Oxygen

Weak and fast pulse(HR>180/mt) AND Extremities cold to touch AND Capillary Refill Time > 3 sec, with or without pallor, or lethargy or unconscious

SHOCK

If bleeding is the likely cause of shock:
- Infuse normal saline 10ml/ kg body weight over 10 minutes
- Stop external bleeding
- Give Vit K IV

If bleeding is not the likely cause of shock:
- Give 10 ml/kg normal saline over 30 min

(Follow STP)

manage airways; start oxygen if saturation
lood glucose; correct low blood glucose

FTER EMERGENCY MANAGEMENT,
ENCY SIGNS ARE ABSENT

The STPs have been converted into “job aids” and wall charts which have undergone expert review and field testing, physically and electronically. A triage procedure exists for 10 common conditions seen in sick newborns. The target audience is medical officers in small hospitals with minimal equipment and drugs.

Apps on android as *AIIMS WHO CC STPs* and on iTunes as *Sick Newborn* have been created and available for downloaded free of charge. This is the second most common downloaded medical apps globally.

9. Technical updates and guidelines

Chairpersons: Drs Erna Mulati (Indonesia) and Burke Fishburn (CDC)

9.1 Elimination of congenital syphilis

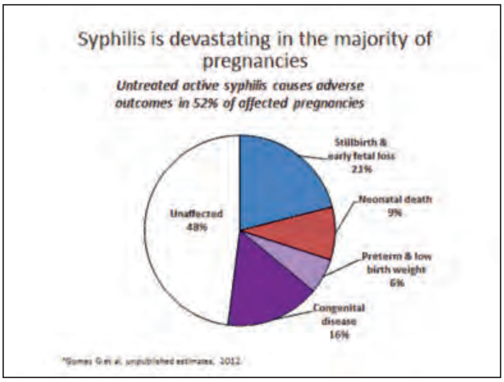
Dr Razia Pendse (SEARO) reported that in the SEAR, 600 000 pregnant women have tested positive for syphilis, which accounts for about 0.6% of the regional population of pregnant women. Untreated active syphilis causes adverse outcomes in 52% of affected pregnancies, such as stillbirth, early fetal loss, congenital diseases, preterm delivery, low birth weight and neonatal death. However, testing and treatment are cheap and effective, and universal screening of pregnant women is cost-effective even in low-prevalence settings.

Dr Pendse reported that the WHO Global Initiative to Eliminate Congenital Syphilis was launched in 2007 with the objectives to eliminate the disease as a public health problem, reduce the prevalence of syphilis among pregnant women and prevent mother-to-child transmission. The 2015 targets for the initiative are to screen more than 90% of pregnant women by their first antenatal care visit and to treat more than 90% of seropositive pregnant women. However, in 2007 there was still no global consensus on congenital syphilis case definition. Diagnosis had relied on clinical history and examination, while diagnostic tests are seldom available and definitions vary widely by country. Therefore proxy indicators have been proposed, based on the percentage of stillbirths attributable to syphilis and the percentage of all infected pregnant women treated by 24 weeks.

The Regional Strategy for Elimination of Congenital Syphilis was developed in 2009 and revised in 2011 to include the opportunity for dual elimination of mother-to-child transmission of HIV and syphilis as they target the same populations, use similar interventions and are typically located in the same settings. The goal of the Regional

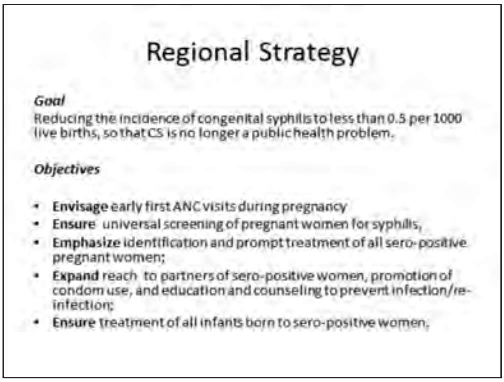
Strategy is to reduce the incidence of congenital syphilis to less than 0.5 per 1000 live births, so that it is no longer a public health problem. This will be achieved through early first antenatal care visits during pregnancy, ensuring universal screening of pregnant women for syphilis, identifying and promptly treating all seropositive pregnant women, expanding the reach to the partners of seropositive women, promoting condom use, education and counselling to prevent infection and re-infection, and ensuring treatment of all infants born to seropositive women.

The challenges in the Region include: limited reliable data on maternal and congenital syphilis; the low rates of pregnant women in some areas seeking antenatal care at least once during pregnancy (50% to over 95%); and similar variations in the level of screening of pregnant women for syphilis (42% to 95%) across countries. All countries have a national sexually transmitted infections (STI) control plan, and Myanmar and Sri Lanka also have a national elimination of congenital syphilis plan. Rapid tests for syphilis are available and used in Myanmar, Sri Lanka and Thailand and on-site treatment is available in India and Myanmar. However, same-day treatment is not available in any country of the Region. Countries like Myanmar and Sri Lanka have linked the elimination of congenital syphilis programme with existing HIV/STI and preventing mother-to-child transmission programmes.


Syphilis is devastating in the majority of pregnancies

Untreated active syphilis causes adverse outcomes in 52% of affected pregnancies

*Gomez G et al. unpublished estimates, 2012


Regional Strategy

Goal

Reducing the incidence of congenital syphilis to less than 0.5 per 1000 live births, so that CS is no longer a public health problem.

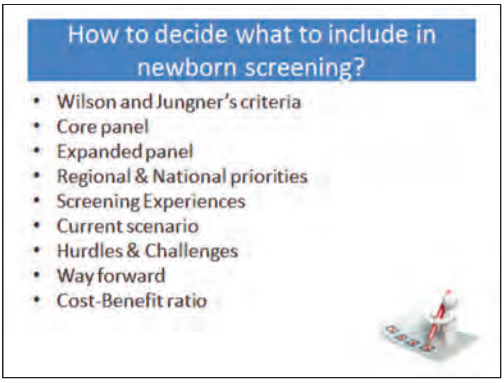
Objectives

- **Envisage** early first ANC visits during pregnancy
- **Ensure** universal screening of pregnant women for syphilis,
- **Emphasize** identification and prompt treatment of all sero-positive pregnant women;
- **Expand** reach to partners of sero-positive women, promotion of condom use, and education and counseling to prevent infection/re-infection;
- **Ensure** treatment of all infants born to sero-positive women.

9.2 Newborn screening: India

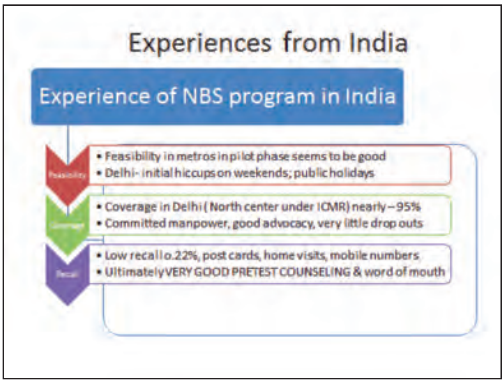
Dr Seema Kapoor reported that in India newborn screening is one of the top 10 public health initiatives. The birth defects burden in India is enormous; of the 27 million annual births, 800 000 babies are born with congenital malformations – 350 000 with G6PD Deficiency, 25 000 with metabolic disorders, 20 000 with Down syndrome, 15 000–20 000 with congenital hypothyroidism and 14 000 with thalassaemia.

Dr Kapoor said that while a lot of discussion is on what to screen for, the Wilson and Jungner criteria have guided the work. Disorders that should be screened should be biochemically well-identified disorders. Incidence in the population and the disorders associated with significant morbidity and mortality should be identified. In addition, effective treatment should be available



How to decide what to include in newborn screening?

- Wilson and Jungner's criteria
- Core panel
- Expanded panel
- Regional & National priorities
- Screening Experiences
- Current scenario
- Hurdles & Challenges
- Way forward
- Cost-Benefit ratio



Experiences from India

Experience of NBS program in India

- Feasibility in metros in pilot phase seems to be good
- Delhi- initial hiccups on weekends; public holidays
- Coverage in Delhi (North center under ICMR) nearly – 95%
- Committed manpower, good advocacy, very little drop outs
- Low recall 0.22%, post cards, home visits, mobile numbers
- Ultimately VERY GOOD PRETEST COUNSELING & word of mouth

Dr Kapoor said that the core panel is country specific and that there has been a lot of debate in India to identify the disorders since 2004. The core panel in India includes congenital hypothyroidism, which is the most common preventable cause of mental retardation, congenital adrenal hypoplasia, G6PD deficiency, and hearing defects. Several states in India like Chandigarh, Goa and Gujarat, and the Indian Council of Medical Research have started a newborn screening initiative. She discussed some of the successful elements of the initiative and its challenges, and noted that newborn screening was actually a model for genomic medicine because it is predictive, preventive and personalized, and as a medical paradigm it is proactive rather than reactive. With the basic aim of disability prevention, newborn screening is as important a public health initiative as immunization and can easily be amalgamated with other horizontal health programmes.

9.3 Newborn screening: Thailand

Dr Suthipong Pangkanon reported that Thailand's national newborn screening programme was launched in 1996 to focus on the incidence of hypothyroidism and phenylketonuria (PKU). The programme now uses four regional centres that screen through heel prick method. He said the incidence of PKU has been reduced while hypothyroidism continues to be a problem. There are currently pilot projects to screen for congenital adrenal hypoplasia and plans to expand the national screening programme to screen for other conditions.

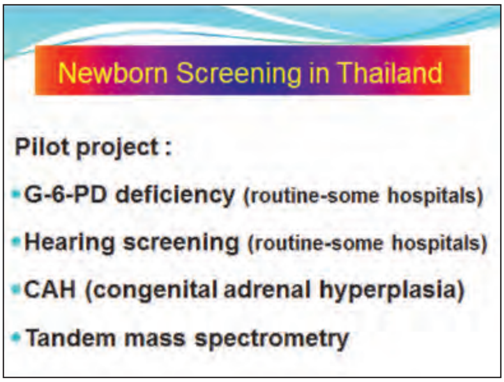
Newborn Screening in Thailand

Operated by Department Medical Sciences, Ministry of Public Health

1. Pilot project in 1992

- Congenital hypothyroidism incidence 1:1,700
- Phenylketonuria " 1:10,000

2. Nationwide screening in 1996



Newborn Screening in Thailand

Pilot project :

- **G-6-PD deficiency** (routine-some hospitals)
- **Hearing screening** (routine-some hospitals)
- **CAH (congenital adrenal hyperplasia)**
- **Tandem mass spectrometry**

9.4 Coordinated approaches to address preterm births and birth defects

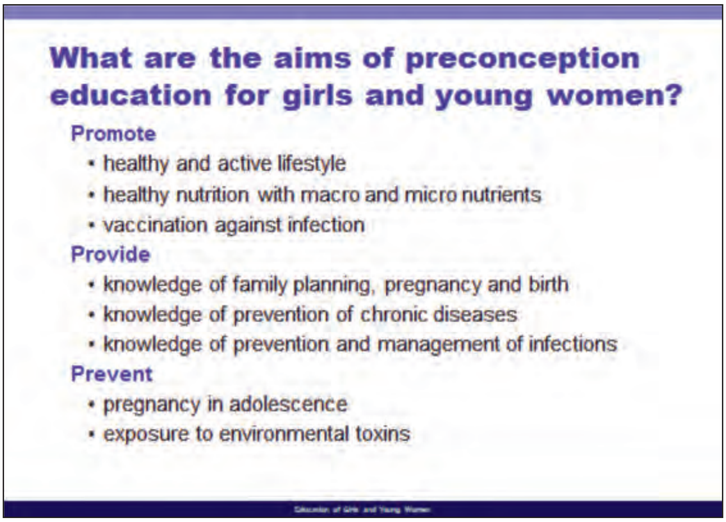
Dr Chris Howson (March of Dimes Foundation) began with a brief history of the March of Dimes Foundation, when United States President Franklin Roosevelt's personal struggle with polio led him to create the National Foundation for Infantile Paralysis at a time when polio was on the rise. The Foundation became known as the March of Dimes as people were asked to donate their dimes ($0.10). The foundation established a polio patient aid program and funded research for vaccines developed by Salk and Sabin, which effectively ended epidemic polio in the USA. The institution then turned to the prevention of birth defects.

Modifiable risks of birth defects and prematurity that could be addressed by preconception education

Diabetes
Under-nutrition
Obesity
Exposure to toxins
Infections
Smoking
Hypertension
Birth spacing
Epilepsy control
Rubella immunizations
Folic acid intake
Alcohol use
Medication management
Age at pregnancy
Early prenatal care

Dr Howson talked about the March of Dimes' prematurity campaign and *Born Too Soon* report and how strengthening preconception care addresses preterm births and birth defects risk factors. Premature birth costs are a high financial burden on society and also take a high toll on families. Babies born just a few weeks early are at risk of severe health problems and lifelong disabilities.

March of Dimes' current preconception care efforts target four priority, evidence-based interventions: family planning strategies, including birth spacing and provision of adolescent-friendly services; prevention and screening/management of sexually transmitted infections (e.g. HIV and syphilis); education and health promotion for girls and women; and promoting healthy nutrition including micronutrient fortification; and addressing lifestyle risks such as smoking, and environmental risks such as indoor air pollution.



What are the aims of preconception education for girls and young women?

Promote

- healthy and active lifestyle
- healthy nutrition with macro and micro nutrients
- vaccination against infection

Provide

- knowledge of family planning, pregnancy and birth
- knowledge of prevention of chronic diseases
- knowledge of prevention and management of infections

Prevent

- pregnancy in adolescence
- exposure to environmental toxins

Education of Girls and Young Women

Dr Howson said these efforts depend on the first step of developing partnerships, especially with nongovernmental organizations and the second step of disseminating data. March of Dimes Global Programs conducts its work through "mission alliances" with nongovernmental partners in target countries that have a share mission to prevent birth defects, preterm birth and infant mortality.

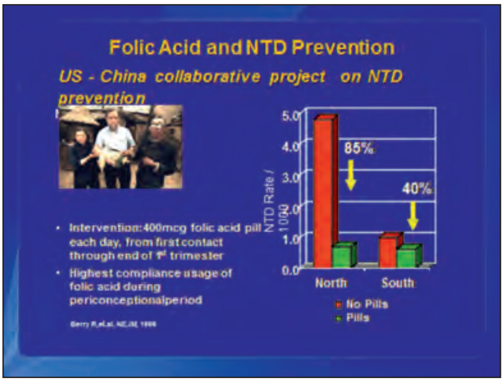
What steps we can take together?

1. Agree to provide preconception health education to girls and young women
2. Partner in creating a model preconception needs assessment tool
3. Develop a multi-country, population-based approach with a standardized curriculum and methods which can be adapted for country use based on the NA findings
4. Incorporate novel methods for reaching and engaging girls and young women
5. Partner with civil society, academic institutions, media and government in supporting this effort

Significant evidence shows that health education for girls has a huge impact on premature births and preventing pregnancy in adolescents. He said that more efforts should be done to reach the largest number of people at the lowest possible costs, and to use innovative approaches to empower girls and women, such as through school-based health, and cell phones and web-based text messaging that can reach millions of people.

9.5 Evidence for the prevention of neural tube defects

Dr Joe Sniezek stated that neural tube defects (NTDs) are serious birth defects that result from the failure of the neural tube to close in the cranial region (anencephaly) or more caudally along the spine (spina bifida) by the 28th day of gestation. This happens before many women are aware they are pregnant. Currently, only 10–15% of the global burden is prevented, though the majority of NTDs are preventable with folic acid. To prevent NTDs, it is recommended that all women capable of becoming pregnant consume at least 400 μg folic acid daily before conception and during early pregnancy. In most countries women of reproductive age do not have adequate folic acid intake because of lack of access to common, readily available fortified staple food products. Supplements are usually given once the woman is pregnant, but this is too late. There is low awareness about the importance of folic acid intake prior to the pregnancy.

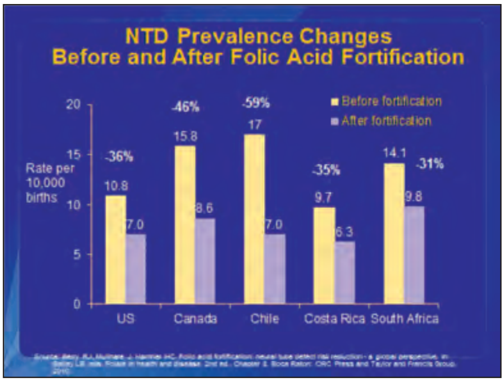


Folic Acid and NTD Prevention

US - China collaborative project on NTD prevention

- Intervention: 400mcg folic acid pill each day, from first contact through end of 1st trimester
- Highest compliance usage of folic acid during periconceptional period

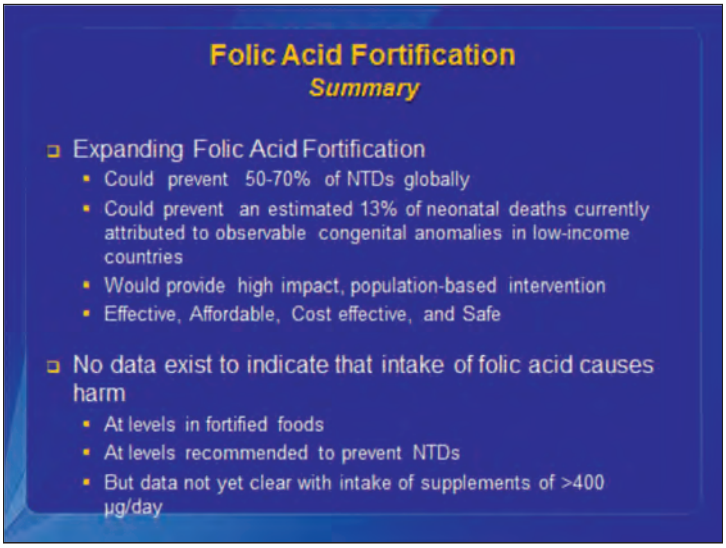
Berry R, et.al. NEJM, 1999



NTD Prevalence Changes Before and After Folic Acid Fortification

Source: Berry RJ, Mulinare J, Hamner HC. Folic acid fortification: neural tube defect risk reduction - a global perspective. In: Bailey LB, eds. Folate in health and disease. 2nd ed.. Chapter 3. Boca Raton: CRC Press and Taylor and Francis Group, 2010

Fortification of wheat and maize flour has been shown to be able to address the global problem of micronutrient malnutrition. Fortification technology has been around for a long time and is a very cost-effective strategy. About 85% of the world's population consumes at least 75 g of a staple food, but only 30% of the 400 million tons of wheat that humans consume each year is fortified. Another barrier to fortification is that in many countries only a small proportion of flour is produced in very large mills. The remaining flour is produced in smaller, local mills that are not able to add the proper premix to their product.



Folic Acid Fortification

Summary

- Expanding Folic Acid Fortification
  - Could prevent 50-70% of NTDs globally
  - Could prevent an estimated 13% of neonatal deaths currently attributed to observable congenital anomalies in low-income countries
  - Would provide high impact, population-based intervention
  - Effective, Affordable, Cost effective, and Safe
- No data exist to indicate that intake of folic acid causes harm
  - At levels in fortified foods
  - At levels recommended to prevent NTDs
  - But data not yet clear with intake of supplements of >400 µg/day

Globally, 75 countries have legislation on fortification and 12 countries have committed to fortification. While folic acid fortification efforts to date have focused mostly on wheat flour, and to some extent on maize flour, there is a growing interest by GAIN and others to fortify rice with folic acid and other micronutrients because of its potential to reach a large proportion of the world's population, especially in the developing world. Dr Sniezek closed by stating that no data exist to indicate that intake of folic acid in fortified foods causes harm, at levels recommended to prevent NTDs. However, there is no clear evidence on any negative effects on an intake of over 400 μg/day.

9.6 Prevention of congenital rubella syndrome

Dr Pem Namgyal of SEARO provided an update on congenital rubella syndrome (CRS) prevention. He informed that at a SEA Regional consultation in February 2013 there was no specific target year set for rubella/CRS control, but that countries were encouraged to review their situation and move towards a definitive target for rubella control. In the SEAR the current reporting system is quite deficient; ten countries report on rubella cases, but only four report on CRS. He said that it was important to understand that improved measles surveillance "unmasks" rubella incidence, as the testing of measles is followed by testing for rubella: even after measles vaccination has been carried out, fever and rash cases appear that are due to rubella.

Dr Namgyal reported on the use of rubella vaccines, including measles and rubella (MR) and the measles, mumps and rubella (MMR) vaccines. The South-East Asian countries using rubella-containing vaccines are Bhutan (MR), Maldives (MMR), Sri Lanka (MMR) and Thailand (MMR). In India, four states are using MMR: Delhi, Goa, Pondicherry and Sikkim. Nepal has already carried out an MR campaign reaching all children 9 months to 15 years, with an introduction into routine immunization expected to follow. Bangladesh has an MR campaign planned for 2013 with plans to introduce it into routine programmes from 2014 onwards.

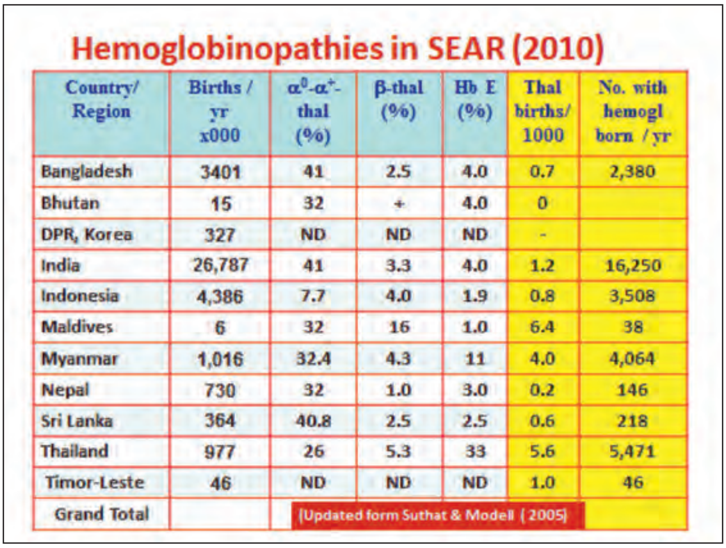
He stated that the time was right for measles elimination and rubella/CRS control in the Region and that rubella must be combined with measles vaccine efforts. Estimates indicate that as much as 47% of the global CRS burden is in the SEAR. The burden of rubella and CRS has been acknowledged, but there has been very little done about it. Additionally, the rubella vaccine is affordable, highly effective (95% with one dose) and safe, whether given singly or in combination.

9.7 Prevention and control of haemoglobinopathies

Dr I C Verma, Director of the Center of Medical Genetics, New Delhi, India, made a presentation on the prevention of haemoglobinopathies in the SEAR. Dr Verma stated that the carrier rate for thalassaemia varies across countries, from 3–5% in India to 16% in Maldives. There are more than 40 000 babies born with sickle cell in India each year (geo-statistical model-based population estimates, Piel et al, Lancet January 2013). However, there is a large variation from state to state and district to district.

According to the Global Burden of Disease study 2010, the years lived with a disability (YLD) from hemoglobinopathies are more than the YLD on account of diarrhoea or tuberculosis. Thus, it is important to develop preventive programmes, especially as the cost of treatment is 4 times higher than the cost of prevention. Control and preventive programmes in India, Sri Lanka and Thailand and Cyprus were described.

Among the most useful prevention programmes are premarital screening, pregnancy screening and prenatal diagnosis depending upon local conditions. Counselling has very limited impact. There is a problem of social stigma. Once the female partner has screened positive then the male partner should also be screened.



Hemoglobinopathies in SEAR (2010)

Country/ Region	Births / yr x000	α^0-α^+-thal (%)	β-thal (%)	Hb E (%)	Thal births/ 1000	No. with hemogl born / yr
Bangladesh	3401	41	2.5	4.0	0.7	2,380
Bhutan	15	32	+	4.0	0	
DPR, Korea	327	ND	ND	ND	-	
India	26,787	41	3.3	4.0	1.2	16,250
Indonesia	4,386	7.7	4.0	1.9	0.8	3,508
Maldives	6	32	16	1.0	6.4	38
Myanmar	1,016	32.4	4.3	11	4.0	4,064
Nepal	730	32	1.0	3.0	0.2	146
Sri Lanka	364	40.8	2.5	2.5	0.6	218
Thailand	977	26	5.3	33	5.6	5,471
Timor-Leste	46	ND	ND	ND	1.0	46
Grand Total		(Updated form Suthat & Modell (2005)				

He shared the key elements for a program for controlling hemoglobinopathies as recommended by WHO.

Elements of Control Program
(World Health Org)

- Political and Financial Support
- Improving Curative Services
- Prenatal Dx in future pregnancies of Affected Couples
- Prospective Antenatal Screening
- Community Carrier Screening,
- Premarital Counseling
- Network of Centers, and National /
- Regional Working Groups

10. Action plan to establish/strengthen networks for newborn health and birth defects

Dr Rajesh Mehta, SEARO, provided guidelines for the country teams to work in small groups and develop their action plans to establish/strengthen networks for newborn health and birth defects. The country teams then met in plenary to discuss functions of the national network, such as to establish a database, advocacy for policy, knowledge management, education and training, quality assurance, research and implementation of pilot projects. Country teams were asked to identify nodal centres for the Newborn Network and the Birth Defects Network, mechanisms to share information, activities and challenges.

The results of their deliberations are presented in Annex X.

11. Panel discussion: reflections and commitments by partners

Chairpersons: Drs VK Paul, AIIMS, Neena Raina, SEARO and Joe Sniezek, CDC

A panel discussion was conducted where major partners commented on the meeting proceedings and their role in supporting newborn health and the prevention of birth defects.

Dr Malalay Ahmadzai from UNICEF said that newborn mortality and morbidity were recognized as major public health problems and that the meeting was very useful in its emphasis on the continuum of care to prevent birth defects at preconception, pregnancy and delivery care. UNICEF is committed to helping with these issues with respect to focus on groups with poor access to health care. India is one of the countries that UNICEF supports for community-based and facility-based programmes, especially for adolescent girls and families, which are more likely to bring about a change. She concluded that there was a need to be deeply concerned about birth defects and that UNICEF would help to leverage resources for these efforts.

Dr K Pappu, India, spoke about the Norway–India Partnership Initiative (NIPI) that supports a mix of health-care services in the four large states of India. Facility-based newborn care is being stressed by NIPI, which can be coupled with India's new national screening of newborns and the work of district information centres. He said that the expertise of Norway would also be tapped for these efforts.

Dr RN Salhan, India, said that the SAARC initiative worked on a "project basis" and covers nearly 1 million births in the SAARC countries. He reported that SAARC is midway through implementation of the project, which was started two years ago. At present SAARC is concerned about survival, but the time may be right to add to the quality of survival.

Dr Rajeev Tandon spoke about Save the Children, which is a child rights civil society-based organization. Newborn health has become a central part of Save the Children's work. Though they have not yet focused specifically on birth defects, they will likely try to include birth defects prevention on their priorities agenda. He agreed that the life-course approach and the role of stakeholders were critical aspects of birth defects prevention, and these components will be included in a Save the Children joint report with the India Public Health Foundation. He added that rapid implementation of research would help catalyse action in this area and fully supported the creation of the new newborn health and birth defects network.

Ms Karen Codling reported on the work of the Flour Fortification Initiative (FFI), which is a network of public, private and civil society partners working together to make flour fortification standard milling practice so that people worldwide are smarter, stronger and healthier. FFI recognizes that countries need a multi-faceted approach to dealing with nutrient deficiencies, and while FFI has traditionally focused on wheat flour and maize, rice would now be included in its scope. To plan a fortification programme, countries should consider local culture and staple food consumption, nutritional and health needs, industry analysis, creation of a multi-sector national fortification alliance and legislation for mandatory fortification. She said that while FFI is not a funding agency, it can provide country efforts with technical support and training on fortification, facilitate collaboration of national stakeholders and the development of national fortification alliances, help to design and guide the national fortification programme and share global lessons learnt.

12. Conclusions and recommendations

Dr Neena Raina of SEARO gave a brief summary of the three-day meeting and presented the following formal conclusions and recommendations:

- The delegates representing the Member States and partners recognized that the decline in newborn mortality has been a challenge in most countries and that the extent of the problem of stillbirths remains unknown. Prevention of birth defects would contribute significantly to addressing these public health challenges as well as reducing lifelong disability associated with birth defects. Therefore, while sustaining the implementation of existing evidence-based interventions to reduce newborn mortality, prevention of birth defects needs to be recognized as a public health priority for achieving MDG4 and making progress beyond 2015 in the Region.
- It is critical to scale-up essential interventions for newborn health during the life-course starting with adolescence, pregnancy, childbirth, and newborn periods, especially focusing on skilled care at birth and the first week of life, the time period when many newborn deaths and intra-partal stillbirths can be prevented.
- Interventions during the preconception period in the life-course must be strengthened to address certain risk factors that are common for congenital conditions like prematurity/intra-uterine growth restriction and birth defects that are significant causes of neonatal mortality, morbidity and disability. This may be integrated into existing adolescent health programmes in the countries as a ‘Healthy Transitions’ package addressed to boys as well as girls. Partnerships with concerned stakeholders should be strengthened for implementation of these interventions.

- Ensuring good quality of care for mothers and newborns is critical while working towards equitable scaling-up of the interventions. Member States should consider adoption/adaptation of resource materials developed by the WHO Collaborating Centre on Newborn Health, including e-courses and standard treatment protocols for improving quality of care of newborns.
- The delegates observed that data and information on perinatal health, birth defects and maternal risk factors need to be strengthened. It was agreed that these data would be integrated within the existing regional and national neonatal-perinatal databases.
- Variables in the existing Regional Neonatal-Perinatal Database maintained by the WHO Collaborating Centre at AIIMS were reviewed and consensus reached on the core and optional set of variables related to maternal and newborn health and birth defects. It was recommended that Network institutions in the Member States should collect and report on this integrated database. Standard summary reports would be shared within the networks (national and regional) for comparison purposes.
- The delegates emphasized that the data and information must be analysed strategically, disseminated and effectively used for advocacy and developing preventive programmes for birth defects with focus on primary prevention and cost-effectiveness.
- Based on the progress and role of the Regional Network on Newborn Health, the delegates recommended the establishment of a Regional Network for Birth defects that would be coordinated by the WHO Collaborating Centre for Genetics at AIIMS, New Delhi. This Network would work in close collaboration with the existing Regional Network for Newborn Health, coordinated by the WHO Collaborating Centre on Newborn Health at AIIMS.
- Member States should move forward to establish or strengthen their National Network for Newborn Health and Birth Defects with the support of their governments and relevant partners.
- The delegates agreed that neural tube defects, congenital rubella syndrome, congenital syphilis, congenital hypothyroidism and thalassaemia were strong candidates for inclusion in national birth defects prevention programmes in the initial phase. National and subnational strategies should be further expanded based on the local situation and new knowledge emerging from surveillance of birth defects.

- It was noted that referral services for care, management and rehabilitation of newborns and children born with birth defects must be strengthened concurrently.

Recommendations for WHO, CDC and partners

- Support Member States to achieve high level advocacy for strengthening newborn health and prevention of birth defects.
- Support national capacity, and provide guidelines and tools for the development, implementation and monitoring of national programmes for surveillance and prevention of birth defects across the continuum of care within existing public health programmes.
- Provide technical support so that the Regional-National Networks for Newborn Health and Birth Defects can effectively contribute to the related national programmes.
- Create opportunities for sharing of knowledge and experience in the field of newborn health and birth defects among Member States and partners and promote research in the Region.

Participants welcomed and endorsed the conclusions and recommendations. Drs Joe Sniezek (CDC), Neena Raina (SEARO) and VK Paul (AIIMS) provided summaries and gave thanks to the organizers, hosts, supporters, and participants. The meeting was then concluded.

Annex 1

List of participants

Countries

Bangladesh

Dr Md Abdul Hoque
Deputy Director, Primary Health Care and Programme Manager, Maternal and Newborn Health
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Annex 2

Agenda

- Inaugural session
- Presentation on the emerging paradigm of newborn health
- Presentation on the global movement on addressing preterm births
- Presentation from the United States Centres for Disease Control and Prevention efforts on the prevention of birth defects
- Presentation on regional initiatives to strengthen newborn health and prevent birth defects
- Overview of prevention of birth defects and maternal risk factors
- Strategic Framework on Prevention and Control of Birth Defects in the South-East Asia Region (2013–2017)
- Progress of regional and national networks
- Presentation on the principles of birth defects surveillance
- Conceptual framework for regional and national networks for birth defects
- Sharing experiences with available models of the neonatal-perinatal database
- Sharing country initiatives on strengthening newborn health and preventing birth defects
- Overview of Birth Defects Surveillance Manual
- Presentation on the communication strategy for birth defects prevention
- Presentation on e-training for newborn health care
- Presentation on the standard treatment protocols to manage newborn conditions in small hospitals

- Development of an action plan to establish/strengthen networks for newborn health and birth defects
- Discussion on recommendation on the variables to be collected on newborn health and birth defects
- Share technical updates and guidelines on:
  - Coordinated approaches to address preterm births and birth defects
  - Country experiences on newborn screening
  - Prevention of neural tube defects
  - Prevention and control of thalassaemia
  - Prevention of congenital rubella syndrome
  - Elimination of congenital syphilis
- Panel discussion on reflections and commitments by partners
- Conclusions and recommendations

Annex 3

Country action plan

1. Functions of national network

Recommended actions		Bangladesh	Bhutan	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Database	Newborn	Sporadic in some institutions	Yes	Yes	Yes	Yes	Yes	In progress	Yes	MoPH/ Government	Yes
	Birth defects	Sporadic in some institutions	Yes	Yes	Yes, in teaching hospital and birthing hospital	Yes	Yes	No	Yes	MoPH/ Government	Yes
Advocacy for policy/strategy and increased investments	Newborn	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Modify	Yes
	Birth defects	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Modify	Yes
Knowledge management	Newborn	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Birth defects	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Education and training	Newborn	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Birth defects	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

Recommended actions		Bangladesh	Bhutan	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Quality assurance	Newborn	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Modify	Yes
	Birth defects	No	Yes	Yes	Yes, for teaching hospital and birthing hospital	Yes	Yes	No	Yes	Modify	Yes
Research	Newborn		Yes	Yes	Yes	Yes	Yes	No	Yes	No/ Proposed later	N/A
	Birth defects	Proposal developed	Yes	Yes	Yes	Yes	Yes	No	Yes	No/ second step	N/A
Implement pilots	Newborn	Yes	Yes	Yes	Yes	Yes	Yes	In progress	Yes	Yes	Yes
	Birth defects	No	Yes	Yes	Yes, selected provinces from 3 regions	Yes	Yes	No	Yes	Yes	Yes

Recommended actions		Bangladesh	Bhutan	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Others	Newborn	Established SCANU in 5 medical colleges and 16 districts hospitals				Neonatal database introduced at IGMH	Dissemination after pilot period. Monitoring and supportive supervision. Share with regional network		Data use at all levels	Supports (IT/ data entry)	
	Birth defects	No		High risk group			Dissemination after pilot period. Monitoring and supportive supervision. Share with regional network		Data use at all levels	Supports (IT/ data entry)	

IGMH=Indira Gandhi Memorial Hospital; IT=information technology; MoPH=Ministry of Public Health; N/A=not applicable; SCANU=Special Care Newborn Unit

2. Identify national nodal centre for national network

Country	Newborn Network	Birth Defects Network
Bangladesh	Bangabandhu Sheikh Mujib Medical University	Bangabandhu Sheikh Mujib Medical University and International Centre for Diarrhoeal Disease Research
Bhutan	National Reproductive Health Programme	National Reproductive Health Programme
India	All India Institute for Medical Sciences (WHO Collaborating Centre)	All India Institute for Medical Sciences (WHO Collaborating Centre) and Fetal Care Research Foundation, Chennai
Indonesia	• West Region: Cipto Mangunkusumo National General Hospital, Jakarta • Central Region: – Sardjito General Hospital, Yogyakarta – Soetomo General Hospital Surabaya, East Java • East Region: Wahidin Sudirohusodo Makassar, South Sulawesi	• West Region: Cipto Mangunkusumo National General Hospital, Jakarta • Central Region: – Sardjito General Hospital, Yogyakarta – Soetomo General Hospital Surabaya, East Java • East Region: Wahidin Sudirohusodo Makassar, South Sulawesi
Maldives	Indira Gandhi Memorial Hospital	Indira Gandhi Memorial Hospital
Myanmar	Central Women's Hospital, Yangon	Central Women's Hospital, Yangon
Nepal	Tribhuvan University Teaching Hospital, Institute of Medicine	Tribhuvan University Teaching Hospital, Institute of Medicine
Sri Lanka	Medical Statistics Unit Family Health Bureau	Medical Statistics Unit Family Health Bureau
Thailand	Ministry of Public Health/Queen Sirikit National Institute of Child Health/other hospitals	Ministry of Public Health/Queen Sirikit National Institute of Child Health/other hospitals
Timor-Leste	Ministry of Health/Medical Association of Timor-Leste (AMTL)	Ministry of Health/Medical Association of Timor-Leste (AMTL)

3. Network members/constituents

Country	Network members/constituents
Bangladesh	• University: Bangabandhu Sheikh Mujib Medical University (BSMMU) • Medical colleges: • Dhaka Medical College • Sir Salimullah Medical College, Dhaka • Shaheed Sharwardi Medical College, Dhaka • Chittagong Medical College • Rajsahi Medical College • Rangpur Medical College • Mymenshigh Medical College • Sher-e-Bangla Medical College • Sylhet MAG Osmani Medical College **Institutes:** • Bangladesh Institute of Research and Rehabilitation for Diabetes, Endocrine and Metabolic Disorders (BIRDEM) • Institute of Child and Maternal Hospital (ICMH) • Maternal and Child Health Training Institute (MCHTI) • Bangladesh Institute of Child Health (BICH) and Dhaka Shishu Hospital • Sylhet Medical College
Bhutan	• 3 Regional referral hospitals • Home Ministry • Local Government
India	Without government funding, 15–20 centres
Indonesia	• Ministry of Health • Ministry of Home Affairs • Indonesia Society of Pediatrics (IDAI) • Indonesia Society of Obstetric and Gynaecology (POGI) • Indonesia Society of Social Obstetrics and Gynaecology (HOGSI) • Indonesia Perinatology Association (Perinasia) • Indonesia Midwives Association (IBI) • Indonesia Pediatric Nursing Association (IPANI) • WHO, UNICEF and United Nations Agencies • Donors and partners (USAID, AusAID, etc.)

Country	Network members/constituents
Maldives	• Tertiary hospitals • Regional hospitals • Atoll hospitals • Private health sector • Nongovernmental organizations
Myanmar	• Department of Health • Programme Managers (Child Health, Maternal and Child Health and Nutrition) • Department of Medical Science • Department of Health Planning • Administrators from selected hospitals • Nodal and focal persons of selected hospitals (neonatologists, paediatricians and obstetricians **Member institutions/hospitals** • Central Women's Hospital, Yangon (affiliated to UM 1) • North Okkalapa General Hospital (affiliated to UM 2) • Sanpya Hospital, Thingangyun • West Yangon General Hospital • East Yangon General Hospital • Insein General Hospital • Central Women's Hospital, Mandala (affiliated to UMM) • 1000 bedded General Hospital, Naypyitaw • Women and Children's Hospital, Taunggyi State Hospital **Extramural hospitals for newborn health data** • Yangon Children's Hospital • 550 bedded Mandalay Children's Hospital • 300 bedded Mandalay Children's Hospital
Nepal	• Institute of Medicine, Tribhuvan University Teaching Hospital, Kathmandu (Dr Laxman Shrestha, Associate Professor) • Paropakar Maternity and Women's Hospital, Kathmandu (Dr Dhana Raj Aryal, Senior Consultant Pediatrician) • BP Koirala Institute of Health Sciences, Dharan (Professor Dr Gauri Shankar Sah, Head, Department of Pediatrics) • Western Regional Hospital, Pokhara (Dr Shri Krishna Shrestha, Senior Consultant Pediatrician) • Kathmandu Medical College, Kathmandu (Dr Sunil Raja Manandhar, Assistant Professor) • Nepal Medical College, Kathmandu (Dr Anya Sharma, Assistant Professor)

Country	Network members/constituents
Sri Lanka	• All specialist institutions – TH, PGH, DGH, BH (94% of deliveries covered) and selected private hospitals • District level Network Coordinator – RDHS and MOMCH • Pilot test – specialist hospitals in Colombo and Galle districts
Thailand	**Phase 1: Pilot project** • Medical schools: 2 sites • Ministry of Medical Health Department • Provincial/regional hospitals – Newborn network members: 5 sites – Birth defects network members: 5 sites **Phase 2: Implementation** • Medical schools: selected sites • Provincial/regional hospitals – Newborn network members: 20 sites – Birth defects network members: 20 sites
Timor-Leste	• Ministry of Health (Maternal and Child Health Department, Child Health Officer) • Timor-Leste Medical Association/Nursing Association (AMTL/AETL) • Hospital (Neonatology Unit, Maternity, ED) • United Nations agencies (WHO, UNICEF) • Nongovernmental organizations, Child Fund, Alola Foundation

4. Mechanisms to sustain the national network

Country	Government mandate	Communication and coordination	Resources
Bangladesh	Government has strong health management and information system and agreed to include in the system	Website: planned Newsletter: planned Meetings: regular with partners National Core Committee for Newborn Health National Working Group for Neonatal-Perinatal and Birth Defects will be formed	Small grant from WHO, Save the Children reflected in the Government Annual Operation Plan
Bhutan	• Formulate policies and guidelines • Strengthen health system including for newborns and birth defects • Mobilize resources	• E-mail group: to be established among all newborn and birth defects networks • Website: reports and information to be shared on Ministry of Health site • Newsletter: to be shared among all the networks • Meetings: quarterly in the districts and annual at the national level	Require technical and financial support for capacity building and strengthening database management system
India	Staff nurse, Data entry operator	Meetings: physical and virtual once every 3 months	ManpowerInfrastructure at site and nodal centres Infrastructure for tools and training
Indonesia	• Develop National Working Group on Newborn and Birth Defects • Develop Birth Defects Registry: (a) Create "a simple web-based registry" (b) Trials in some pilot hospitals (teaching and birthing) (c) Evaluate available birth defects form (neonatal essential and young infant Integrated Management of Child Illness) • Create protocol for prevention/management (a kind of algorithm) based on Birth Defect-Registry • Establish national surveillance mechanism	• E-mail Group: to be developed • Websites: – www.kesehatananak.depkes.go.id – www.idai.or.id – www.pogi.or.id – www.perinasia.com – www.ino.searo.who.int • Newsletter: Warta Gizi-KIA, Buletin IDAI, Majalah POGI Magazine, Perinasia Magazine • Regular Working Group meetings • Seminars and scientific meetings/workshops • Media campaign	Ministry of Health, WHO and United Nations agencies, donors and partners

Country	Government mandate	Communication and coordination	Resources
Maldives	Yes	• E-mail • Website • Meetings • Teleconference	Financial support Human resources Technical support
Myanmar	Approval from Ministry of Health	• E-mail Group • Website: under development • Newsletter: to be established/ quarterly • Meetings: quarterly • Formulation of annual work-plan • Annual Evaluations	Resource mobilization through various donor agencies and mechanisms
Nepal	Yes for newborn database	• Email Group • Website • Meetings	WHO funded
Sri Lanka	The perinatal-newborn database will be incorporated into the existing system	• Meetings: regular reviews (institutional, district and national) • E-mail Group • Website • Newsletter	Professional inputs Human Resources (units, data entry, data management at nodal level) Formats, guidelines, training materials, logistics (IT, communication)
Thailand	Government/ Ministry of Public Health	• Email group • Video conference • Meetings	Medical services department/WHO/ UC Supporting group: Secretary/IT/data entry
Timor-Leste	Government policy (Ministry of Health)	• Email Group • Website?? • Newsletter • Meetings : every quarter or semester	Pediatrician, Medical Officer, Pediatric Registrar, Nurse, Pharmacyst, IT

5. Expected challenges for establishing or strengthening national networks for newborn and birth defects at the country level

- Sustainability (coordination and communication)
- Information technology (computers, networking, maintenance)
- Database management (collection, regular updates, quality of data, uniformity)
- Manpower (frequent transfer of trained human resources, attitude-resistance)
- Integration (into existing registries, health management information systems, and vital registration)
- Policy priorities
- Logistics (geographical)
- Finances
- More requests from specialists

6. Actions to be taken in 2013–2014

Country	Establish national network				Build capacity		First data summary	National network meeting	Proposal for implementation project
	Obtain Ministry of Health concurrence	Dialogue with stakeholders	Identify institutions/ agencies	Launch national network	Database training	Birth defects surveillance teaching-of-trainers			
Bangladesh	July–Sep 2013	July–Sep 2013	Ongoing	July–Sep 2013	6 monthly	Yes	Q1 2014	6 monthly	Yes
Bhutan	June 2013	June 2013	June 2013	NB: Dec 2013 BD: Dec 2013	August 2013	August13	Jan 2014	District: quarterly National: annual	Yes
India	3 months	3 months	3 months	3 months	6 months	6 months	12 months	6 & 18 months	Yes
Indonesia	May–July 2013	May–July 2013	May–July 2013	May–July 2013	2015	2015			
Maldives	June–July 2013	July–Aug 2013	Sep–Oct 2013	Nov–Dec 2013	Jan–Mar 2014	Jan–Mar 2014	Dec 2014	Dec 2014	
Myanmar	July–Sep 2013	July–Sep 2013	July–Sep 2013	July–Sep 2013	Oct 2013–Mar 2014	Oct 2013–Mar 2014	April–June 2014	From Oct 2013	Yes
Nepal	June 2013	June 2013	June 2013	NB: July 2013	Done	July13	NB: Sep 2013	Ongoing	Yes
Sri Lanka	National-level meeting: May 2013			April 2014	Revise: database: July–Sep 2013			May 2013	Oct 2013–Mar 2014
Thailand	Q1 2014	Q2 2014	Q3 2014				2014		
Timor-Leste	Until Q2 2014	Until Q2 2014	Until Q1 2014	2015	Until Q2 2014	Until Q2 2014	Q4 2014	Ongoing	

7. Expansion plans

Country	Expansion Plans (2013–2014)	Other points/plans
Bangladesh	Expansion of the network	–
Bhutan	• Expand to 20 district hospitals 2014–2015 – Capacity building – Supplies and equipment • Develop and implement information, education and communication (IEC) and advocacy programmes on birth defects • Expand and strengthen online database management	Need support to take part in international seminars and workshops to update knowledge and skills on newborn and birth defects databases
India	• Expansion of the network • Targeted research • Population-based focus • More birth defects to be included • Quality improvement in neonatal database	Create surveillance centres at all medical colleges with dedicated staff
Indonesia	–	• Champion and commitment • Need for resources and sustainability - financial and personnel • Quality control and assurance
Maldives	–	• Birth defects prevention included in the draft National Reproductive Health Strategy 2013–2017 • Micronutrient policy in the process of endorsement: food fortification, strengthened regulation on imported iodized salt, etc. • Law passed on tobacco control • Law passed on thalassaemia control • Planned to start folic acid supplementation programme • Thalassaemia prevention and management: – Capacity building for prenatal diagnosis, genetic counselling, laboratory technicians – Creating awareness
Myanmar	• Consolidation • No plans for expansion • Continue data entry implementation	Close links with the WHO South-East Asia Regional Office and the WHO Collaborating Centre, the All India Institute for Medical Sciences

Country	Expansion Plans (2013–2014)	Other points/plans
Nepal	Include other hospitals in the network for newborns and birth defects: 6 in 2014 and 8 in 2015	–
Sri Lanka	–	–
Thailand	• Knowledge management • Sub-nodal centre/network members/ training/quality assurance set-up • Project enrolment/nodal/subnodal/network members	Support from the WHO South-East Asia Regional Office • Hardware • Internet • Educational and training programme
Timor-Leste	Expand to other hospitals if pilot project succeeds	–

Group Photograph: South-East Asia Regional Network Meeting on Strengthening Newborn Health and Prevention of Birth Defects
23–25 April 2013, New Delhi, India

Despite a significant reduction in under-five and infant mortality, newborn mortality remains high in the South-East Asia Region. The World Health Organization Regional Office for South-East Asia has harnessed the leadership on newborn health by the establishment of the Regional Network on Newborn Health.

WHO-SEARO has recently developed the Regional Strategy for Prevention and Control of Birth Defects in collaboration with Member States. It would be useful to establish a regional network that supports implementation of this Regional Strategy, and surveillance and prevention activities in the countries.

The regional network meeting on strengthening newborn health and prevention of birth defects was organized and hosted by the WHO Collaborating Centre – the All India Institute of Medical Sciences – with the support of the Regional Office and the Unired States Centers for Disease Control and Prevention. National programme managers on newborn health and birth defects, members of regional newborn networks, birth defects experts, WHO staff from the regional and country offices, and representatives from United Nations agencies and partners organizations attended the meeting. Consensus was reached to establish a Regional Birth Defects Network that would function in close coordination with the regional network on newborn health. Recommendations were developed for the Member States as well as for WHO, CDC and other partners. Proposed action for the next two years were also developed from each participating country. The report provides the summary of proceedings of the meeting.

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